

At the Foot of Table Mountain: Paediatric Tuberculosis Patient Experiences in a Centralised Treatment Facility in Cape Town, South Africa

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ABNKAT001

June 2014



Thesis Presented for the Degree of

Doctor of Philosophy

Division of Social Anthropology

School of African & Gender Studies, Anthropology and Linguistics

Supervised by Dr. Susan Levine

Financial Assistance from UCT Interim Funding and Dr. Helen MacDonald at the University of Cape Town is hereby acknowledged. Views expressed are those of the author, and cannot be attributed to any other entity.

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Acknowledgements

No story can be told without a story teller. I was fortunate to be surrounded by many stories, and those who were brave enough to explain often difficult circumstances with candour, delicacy, laughter and tears. I would like to thank the children, families, volunteers and all of the staff of Brooklyn Chest Hospital for their time, understanding and exemplary patience. You all let me into your world ‘inside’ the gates of an incredible institution that is so much more than *just* a hospital. Your work and stories; both personal and intimate demonstrate devotion to children’s health and your profession. Thank you for everything. To Dr. Early and the teachers; you are super heroes. You make such an incredible difference in the lives of children who walk through the gates of BCH, and you always made me feel at home in the hospital; much like the patients whose lives you touch daily. Thank you.

Children’s Radio foundation lent a different dimension to methodological approaches during research. Thank you for your expertise, time, resources and continued interest in the children’s experiences at BCH and beyond.

I am very much indebted to my supervisor Dr. Susan Levine. Thank you for your boundless energy and thoughtful reflection on my writing style and the many challenges I encountered both in and outside of the field. Your unrelenting support during my time at UCT is appreciated, perhaps more than you may ever understand. It was also through Susan that I was rewarded with the insight and acute perspective of my editor Joanna Simon. Your editing eyes were very helpful.

Dr. Helen MacDonald: I don’t really know where I would be without your encouragement and guidance. You have acted as an initial inspiration to work with TB patients in the first place! You challenge me and my writing, my brain and my expectations of myself. I couldn’t ask for a more supportive mentor. I would be remiss if I didn’t mention the gracious funding you and UCT have provided me throughout the years. Interim Funding from UCT allowed me to push through difficult times, and pursue my research further. Thank you for the generosity and (always) fair appraisal of my work and professional aspirations.

Marilyn Monroe once said, ‘If you can’t handle me at my worst, you sure as hell don’t deserve me at my best’ ...No truer words were spoken when applied to the unrelenting support of my

family in South Africa and in the United States. My families both here in Cape Town and overseas, thank you for your support through open ears and non-judgemental hearts. Those in Cape Town: Arthur, Siya, Llewellyn, Dina, Natalia, Navin, Gary, and Genna, thank you for propping me up during arduous fieldwork experiences, and rants about things that may have felt very small but were, to me, quite important in size and magnitude. My family in the United States, especially my father, thank you for listening to my endless ‘anthropologizing’ of, well, everything. Even when you didn’t understand what I was talking about, it always felt like you cared. Dada, in your infinite (and witty) wisdom; especially in your encouragement to ‘write like the wind’. To Cheri: Thank you for tea breaks, open ears, and a place to hang out when I needed a break.

Lastly, to the two main men in my life, one human person and one dog person. Lyle, I could not ask for a better partner, best friend, and confidante. Thank you for trying to understand the ways I view the world. Your gentle nature and sense of fairness are well-suited to my less reasonable qualities. Thank you for your patience and reassurance, love you big time pal. Lastly, to the dog person in my life, Leo. Although we lack a shared comprehensive language, thanks for accompanying me through my academic career at UCT. You’ve been my audience for endless recitations of panel presentations, edited, read-aloud drafts, and papers I may never publish. Regardless of everything, thanks for putting up with me big guy.

I dedicate this work to TB patients I have come to know over the past 10 years living in South Africa: those who are still alive today and those who were lost all too soon. *Ndiyanibingelela.*

Plagiarism Declaration

Plagiarism is to use another's work and pretend that it is one's own. I have used the author/date convention for citation and referencing. Each contribution to, and quotation in this research project from the works of other people has been attributed, and has been cited and referenced. This project is my own work in concept and execution.

Signature:

Signed by candidate

Date: 2.6.2014

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Abstract

The following thesis traces one year of ethnographic research within a contemporary Tuberculosis (TB) treatment facility in Cape Town, South Africa. Brooklyn Chest Hospital (BCH) is considered to be a provincial TB centre of excellence in the Western Cape (Parsons et al 2010) and as such, caters to both adult and paediatric TB patients. While there are other similar facilities in South Africa, BCH specializes in paediatric TB and is the only facility of its kind in the Western Cape Province. Many (but not all) paediatric patients at BCH came from troubled social circumstances. Poverty, violence, substance abuse, and illness featured prominently in their lives. The thesis documents the many entanglements TB presents to patients, their physicians, teachers, and nursing staff in the context of Cape Town. Throughout the thesis, my argument is multi-faceted. Children are configured and classified in different ways: via Biomedicine, children rights and ethics discourse, volunteers working at the hospital, the hospital school space, and through the metaphorical and real burden of time and tedium one experiences within an institutional setting.

While focused on children and their experiences, this thesis does not claim to be solely ‘child-centred’. Rather, I bring together different perspectives from nurses, doctors, volunteers, family members, and children themselves to re-create the social and material life of a hospital. In doing so, I focus on the category of the child. Configurations- how people make sense of children and their experiences- underlie the process of paediatric patient making. The child is formulated into different categories which are unstable and unsettled. The ‘child’ appears here in many forms: the child as a biomedical object, a student patient, the child ‘in need’, and one who is burdened by time.

Keywords: Children, paediatric Tuberculosis (TB), Cape Town, South Africa, sanatorium

List of Abbreviations

(In Alphabetical Order)

AIDS - Acquired Immunodeficiency Syndrome

ARVS - Anti Retrovirals

BCH - Brooklyn Hospital for Chest Diseases, Brooklyn Chest Hospital, Brooklyn Chest, Brooklyn

CSL - Community Service Learning

DoH - Department of Health

DOTS - Directly Observed Therapy-Short Course

ECD - Early Childcare Development

HAART - Highly Active Anti-Retroviral Therapy

HCW - Health Care Worker

HIV- Human Immunodeficiency Virus

NGO - Non-Governmental Organisation

NPO - Not for Profit Organisation

TB - Tuberculosis

TB-M - Tuberculosis Meningitis

MDR-TB - Multiple Drug-Resistant Tuberculosis

XDR-TB - Extensively Drug-Resistant Tuberculosis

WHO - World Health Organisation

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Author's Note

Much of the following work is written in the first person narrative voice. As a student of anthropology, I consider this to be one of the many merits of the discipline; to be able to 'write in' the intimacy of one's self in relation to those who participated in the research. The written product reflects this desire. It is also for this reason of intimacy that I chose to exclude any photographs or visual depictions of the children I worked with. There are no chest x-rays here to view, no self-portraits to identify individuals. Instead, the photographic material included is largely shot from the perspective of the children in Ward 3 and what they wanted to show you, the reader. In addition, all names in this work are pseudonyms, and many of the children chose their names for the final written product.

Although race has been recognised as a social construct, Apartheid-era policy in South Africa depended upon the classification of populations along racial categories. Terms such as 'Black', 'White', and 'Coloured' are used according to how research participants self-identified. These terms were employed when participants used them in conversation. Twenty years since the transition from Apartheid to a democracy, the South Africans I worked with identified, and spoke, 'in colours'.

South Africa (and Cape Town more specifically) is an inherently complex place. With 11 official languages, linguistic diversity presents inherent translation challenges from Afrikaans or isiXhosa to English (or any combination thereof). Translations were provided by the speaker to maintain the integrity of their meaning. Excerpts from verbal transcripts have *not* been edited to reflect formal English grammar. The excerpts included in the work are presented as I heard and understood them verbatim. I also include field notes which *have* been minimally grammatically groomed post-event. In conversations some text has been italicised by my own hand for emphasis.

Chapter One: On the Inside, Looking Out

Through the Gates

Mena¹ and I sat on the front *stoep*² sharing an apple. Sunlight streamed through the windows of the glass enclosed porch to Ward 3. We exchanged few words; Mena was too tired to go back to school. Suddenly, Gift³ burst through the doors without warning. Normally the buzzer would ring in the office, activated by a visitor outside the ward trying to enter. I hadn't heard the buzzer ring, and yet, here stood Gift. He ran past us and into the main sleeping area for the older children. He fumbled around under the white steel bed frame and produced a pre-packed bag. Mena looked up at me and said, 'He's gonna go Kate'.

'G, where are you going?' There was no reply. 'G? Nurse Jones? Gift is here.' The older nurse walked onto the stoep from the office and asked, 'Gift, please talk to me. What's happening? Why are you crying?'

Gift refused to speak. My phone rang. It was my supervisor. 'Hi, I can't talk.' Gift tried to push past me. 'G, where are you going? Ok, I'll call you later. Sorry, we have a bit of a situation here. One of my kids is trying to run away.' I ended the call. 'Gift? Boeti⁴, come here, let's talk.'

What was the best course of action to take? Gift, at fourteen years old, was determined to leave. But *where* was he going *to go*? I had heard many accounts of runaway patients, but I had never witnessed it first-hand. Gift continued to fight against Nurse Jones, Mimi the cleaner and me as we tried to make sense of the situation. He would not speak, he just cried.

Nurse Jones persuaded me, 'Let him go Kate, it's better. The guards will get him. We'll call them now.' 'Nurse, are you sure?' 'Yes, just let him be. They'll speak to him. It will be good for him to speak to those men. You know *mos*⁵; he may need that right now.'

We stared out the windows of the enclosed stoep, through the chain link gate, and watched as the little boy hurried across the grassy, sandy expanse separating Ward 3 from the parking lot. He carried his bag and stumbled a bit on the mole holes that pocked the gritty terrain. Within

¹ A pseudonym

² porch

³ A pseudonym

⁴ Vernacular isiXhosa or Afrikaans for 'brother'.

⁵ Afrikaans vernacular of 'you know'.

less than a minute, the electric exit partition closed and security men clad in maroon and black filtered out of the front gate kiosk. An older guard approached Gift just before he arrived at the entrance and brought him into a one-armed embrace. They spoke and the guard consoled him. They disappeared into the gate house. Mimi reflected, ‘He’s just a boy. What is he thinking? And to go where? What will happen to him in that big world out there? He has a mother and father, nuh⁶? And then?’

Nurse Jones shook her head and replied flatly, ‘No, he can’t just run away. No one can.’

Mena finished her apple and I removed her back brace. When she was admitted, her TB meningitis (TB-M) was so severe doctors feared she was going to be paralysed. I tucked her in to bed and left Ward 3. As I looked back at the security kiosk, a wave of déjà vu washed over me. I remembered an initial trip to the hospital for my PhD research. As I left that afternoon, a female patient approached my car and implored me to ‘take her away’. When I asked where she was going, she replied, ‘Anywhere’.

The school sat on the opposite side of the complex. The wind whipped through the maze of lemon cream, red-roofed buildings, kicking up wisps of sand. Through the palisade perimeter fencing I saw the other children and teachers assembled on the front porch of the school. I unlocked the front gate and let myself in. I explained to the headmistress, Theresa, what had transpired. She explained that Gift had asked to use the toilet. Theresa speculated that he took the front door key from her desktop and snuck out. After locking the metal gate, he probably flung the keys back through the door, onto the floor, where she had found them. He arrived minutes later at Ward 3 at the Brooklyn Chest Hospital (BCH), my PhD research site.

Gift’s attempted escape was not an uncommon occurrence; it represented an accumulation of frustration, confusion and desperation some patients experience while living within the facility. In order to fully contextualise the events leading up to his attempted flight from BCH, it is necessary to read Gift’s story accompanied by those of other paediatric patients during the time of my research from November 2011 to 2012.

This research conveys a year in the life of a present day Tuberculosis (TB) sanatorium from the perspectives of child patients, doctors, nurses, and volunteers living and working at BCH. Throughout the introduction, I introduce the different ways in which TB has been configured

⁶ Meaning: ‘No?’

epidemiologically, pathologically, historically, and finally within the context of South Africa. An analysis of the construction of the figuration of the child runs parallel to this. Children are imagined in unique ways, both globally and locally. They are shaped into categories: as patients, dependents, recipients of care, as well victims of circumstances beyond their own control. The following hospital ethnography illustrates the different ways children, time, and TB have been shaped and re-shaped throughout the ages and in different disciplines.



Figure 1: entrance to BCH and signage

At the Foot of Table Mountain

My interest in working with paediatric TB patients stemmed from my MA at the University of Cape Town in 2010. I worked with adults who were being treated for Multiple Drug Resistant-TB (MDR-TB) and Extensive Drug Resistant-TB (XDR-TB) in a decentralised ‘patient-centred’ treatment programme. During that time, I heard accounts of BCH or ‘Brooklyn’ as it was frequently referred to by patients both past and present. BCH was described as a ‘prison’ and others alluded to it as a place where one ‘goes to die’. It seemed to me, at the time, that the institution was shrouded in negative connotations. BCH’s reputation seemed to be built upon a robust collection of horror stories, urban myth and recycled facts, which may have mutated and twisted over time. Yet, amidst overtly negative accounts, there were stories lauding the knowledge gained through the experience of living in BCH. This alternative telling aligned experience with a necessary isolation from society. Isolation provided a lens with which to better understand treatment and the responsibilities beyond a prolonged (and sometimes repeat) stay at BCH. Some adult patients argued that an individual emerged equipped with skills ‘to cope’. I was intrigued with how patient experiences of Brooklyn lent themselves to increased

drug adherence, stigma, perseverance, and other times despair and eventual re-admittance. In that body of research, my research experience with children was limited, but the interest was piqued nonetheless.

I had many unanswered questions. How would children formulate models of disease transmission and notions of trust, medicine taking and diet, and ultimately, responsibility to themselves as well as others? How did the understanding of a disease shift when one worked with children? This gradual line of questioning propelled my interest to work with paediatric patients living within a contemporary sanatorium. I wanted to understand the challenges they faced as minors, patients, children, and of school-going ages, isolated from everything that seemed 'normal'. How would children's understandings of their isolation experience differ from adult's accounts? Who was responsible to ensure they received necessary treatment when they became ill? Who was deemed trustworthy and why? How do children make sense of circumstances which (in this case) were largely out of their control? How did children make a home in a foreign environment?

BCH is in a working class area in Cape Town called Brooklyn. In South Africa during Apartheid, populations were forcibly relocated to different geographic locations according to racial criteria. Brooklyn was an area reserved for impoverished or uneducated white populations. It was one of many 'sandwich' neighbourhoods on the periphery of Cape Town, in the Western Cape Province of South Africa. BCH sat on land which was originally a privately-owned farm. The farm eventually became a government run farm hospital which served white clientele only. Today, the facility accommodates the only specialised paediatric TB and DR-TB ward in the city of Cape Town and treats an entirely different demographic in comparison to its inception. While Brooklyn remains a working class area, there were more immigrants than previously. One nurse explained to me:

‘You know, back then it was poor *whities*⁷. Now all the Nigerians is here, those people from outside, and *Slamse*⁸. Even so, the drugs are worse. The *tik*⁹ *koppe*¹⁰. You can see the *prossies*¹¹ on the corner. Maybe it’s changed, but not for the better. I certainly wouldn’t live here.’

Her observations spoke to the influx of immigrant populations, the increased availability of the drug *tik* and the sex workers who I saw daily as I drove to and from BCH. For her, Brooklyn, as a neighbourhood, was not ideal.

BCH housed 320 beds for TB inpatients, of which 60 were paediatric cases. The research involved over 50 children, all of whom were diagnosed with a severe form of TB, often complicated by a simultaneous diagnosis of HIV or other opportunistic infections. Most of the children admitted to the hospital came from troubled social backgrounds accompanied by impoverished circumstances, physical abuse, sexual abuse, drug addiction and alcoholism, to name a few. BCH housed two paediatric wards, Ward B and Ward 3. Ward B accommodated 40 beds for children under 5 years old and those classified as new arrivals or still infectious. Ward 3 housed older children, generally ranging from 5 to 15 years of age. Children 16 years of age and older lived within the exclusively male or female adult wards, which were classified along the severity and type of TB. The majority of the paediatric patients at BCH were admitted because guardians were not able to continue care for them, either through financial strain or inability. In addition to these factors, almost all of the children living there were extremely ill upon arrival. They required the extra care and support Brooklyn provided for all patients while they recuperated. BCH furnished patients with three meals daily, clothing, a bed, shelter and extremely expensive healthcare which would not otherwise be affordable or accessible. Most of my research time was spent with Ward 3 children. We did almost everything together: went to school, ate lunch or dinner, drank pills and played, a lot.

With infectious diseases like TB, statistics, WHO-generated data, historical texts, news casts and media coverage are readily accessible. The human experience of TB demonstrates the complexity and interconnectedness of many relationships, far beyond the ‘bug’¹² and its host. These relationships and links demonstrate the fractured social, historical, political and economic realities those in abject poverty experience in unequal proportions globally.

⁷ White people

⁸ Vernacular for Muslims

⁹ A type of methamphetamine

¹⁰ Afrikaans for head- meaning ‘drug head’ or specifically, ‘tik head’

¹¹ Sex workers

¹² A metaphor to describe the TB bacteria

Generally, adults occupied the centre of the TB discourse, to the extent that TB in children was a non-entity. Paediatric TB received little recognition from the WHO, much less the children who were living (and dying) from it in developing countries. The social experience of people who have TB is a vital starting point to locate significance and future implications within the lived experience of TB. Individual patient narratives in this sense offer a nuanced understanding of the challenges children in the developing world face daily; whether they are deemed 'ill' or 'healthy', by themselves or other qualifying bodies.

While there are anthropologists working in a variety of developing contexts addressing TB, this thesis focuses on the experiences of children hospitalised for TB in Cape Town, South Africa. There are different treatment paradigms and programs underway globally to address TB control. Erin Koch for example, (2011, 2013) examines Directly Observed Therapy-Short Course (DOTS) implementation in post-Soviet Georgia with attention to the way tuberculosis becomes a social disease. Ian Harper's work in Nepal (2005, 2006) focuses on the experiences of patients, also within a DOTS program. These authors consider the social actors, transnational partnerships and powerful organizations that create standardised protocols which in turn are implemented for local TB patients. Their research sheds light on the regional specificity of TB, and what is *at stake* for patients. DOTS-focused research is central to an anthropology of TB, but is not the focus of this hospital-based ethnography. Inpatient treatment differs significantly from a DOTS approach, and the following thesis explains why that is, and what the implications are for child patients and their carers.

This research marks a departure from a DOTS-focused, or adult-centred inquiry through exploring the lives of children and those who work alongside them in a clinical environment. With my focus on the relationships between children, hospital staff, teachers and volunteers, a different area of inquiry is opened up. Additionally, a glimpse of the social realities children face *outside* of the institution are evidenced through their narratives here.

The analytical thread that runs through this thesis are the 'figurations'¹³ of children and the figurations of Tuberculosis. The work of Annemarie Mol (2002) is essential in this regard, as it is the *doing* aspect that warrants merit and consideration. In her work with people suffering from atherosclerosis in a Dutch hospital, Mol (2002) addresses the ways in which a disease is *acted upon*, and conveys that this entity is different every time. She states: '...No object, no

¹³ Lending the term from Castaneda, 'figurations' (2002)

body, no disease is singular...’ (Mol 2002:6). Mol presents the plural nature, the multiplicity of atherosclerosis- as it may appear to a patient, how it may be treated by a doctor, how it may be translated in a diagnostic test, or a surgical intervention on an artery- all of these are *different* representations of the *same* medical condition. Although atherosclerosis is remarkably different from TB, Mol’s analysis is instructive. Following her lead, the sections below detail figurations of Tuberculosis; its pathology, its prevalence in children, the topography of TB, and lastly, the inequalities and urgency associated with curbing drug-resistant strains in South Africa.

‘The greatest killer in history’¹⁴

Because of its natural history, the transmission of *M. tuberculosis* is difficult to study; *M. tuberculosis* is spread by airborne droplets of respiratory secretions expelled by an infectious person to a susceptible host, who may or may not be known to the source (Riley, Nyaka 1959 cited in Castro and Jaffee 2002). The bacterium can remain latent as an asymptomatic infection for years, and the source of such infections can be difficult to ascertain. Thus, the places and persons involved in a chain of transmission may be puzzling to identify or exclude (Castro and Jaffe 2002).

TB is an ancient disease with known origins tracing back to 8000 B.C. (Reynolds 2010). As an airborne, highly contagious bacterium it is likely that more people have died from TB than any other infectious disease in history (Daniel 2006:1862). Although Robert Koch isolated the bacterium in 1882, it would only be some decades later that a first line cure, streptomycin, was developed. Despite this finding, TB has emerged with renewed vigour in recent years, once again establishing itself as the ‘grandfather’ of infectious diseases.

The prominence of TB in history is noteworthy. There is evidence of TB in the Biblical texts Leviticus and Deuteronomy (Daniel & Daniel 1999). The Greeks knew TB as ‘phthisis’, and it served as the basis for Hippocrates’ writings in *Book I, Of the Epidemics* (Daniel 2006:683). There has been abundant archaeological evidence of TB provided from mummy DNA and bone remains from the Americas, as well as Colombia, Peru and Egypt (Cave 1939). In India there is textual evidence of TB dating back to 3,300 years ago (Daniel 2006: *ibid*); in China literary references start around 2,300 A.D. (*ibid*). In northern Europe, TB was thought to be

¹⁴ Selgelid (2008:10)

hereditary, whereas in the south, TB was considered infectious by its very nature (Daniel 2006:684).

Pathology of TB: Figuration One

To many, it is unimaginable that *mycobacterium tuberculosis* (the bacteria which causes TB infection) still exists in human populations. It is, for the most part, a bacterium which caused (and continues to cause) a forgotten disease. *Forgotten* because it has been treated successfully and on a large scale in the majority of the developed world. However, in the developing world, and in South Africa especially, TB is an extremely relevant, if not urgent, public health concern. South Africa has the second highest TB incident rate in the world, with the highest prevalence in urban and peri urban parts of the Western Cape Province (MSF 2008-2009, WHO 2010, National Strategic Plan to Stop TB 2012-2016). The co-existence of HIV and AIDS has contributed substantially to the continued presence of TB in Southern Africa. In South Africa specifically, 70% of those infected with TB are also co-infected with HIV (National Strategic Plan to Stop TB 2012-2016).

TB is airborne. One acquires the *risk* of infection through breathing. When aerolised particles of saliva containing *mycobacterium tuberculosis* are ingested, there is a risk for infection. These saliva particles are emitted and propelled into the air through sneezing, coughing, singing and even speaking (Wells 1955, Riley and O'Grady et al 1962, Schaaf and Zumla 2009). An airborne, primary infection is generally acquired via someone who has *active* pulmonary TB. If an acid-fast dye stain renders a sputum smear that is *smear positive* it means that the sample contains tubercle bacilli. Children generally develop TB differently; they develop primary progressive infections. This means that they may have been exposed to someone with active TB, but the infection may manifest within a year to two years of exposure. These cases are smear negative, meaning they have TB but are not considered a significant source of infection to others in their community. Adults are capable of providing sputum samples, i.e. coughing to emit a productive sample of sputum emanating from the lungs. Children are not always as able to perform this, making diagnosis tedious and often a very prolonged endeavour.

It is also important to note that TB, as an aerobic bacterium, is oxygen-loving. This is a fundamental reason why TB *usually* infects the lungs as the pulmonary cavity is an oxygen-

rich environment. This type of infection is called pulmonary TB, but there are many types of TB. Extra thoracic TB refers to TB outside of the brachial and pulmonary areas. TB-Meningitis (TB-M) is a term used to denote TB infection in the meninges of the brain. TB can manifest and ‘activate’ almost anywhere in a human (or animal) body. Other types of infection include glandular TB, TB in the bones (most notably spinal TB) and abdominal TB amongst others. There are also drug-resistant strains previously mentioned: Multiple Drug-Resistant TB (MDR-TB) and Extensive Drug Resistant TB (XDR-TB). MDR-TB is defined as a resistance to first line TB drugs, while a resistance to second line TB drugs characterises XDR-TB. Often these two are grouped and called Drug Resistant TB (DR-TB). December 2011 evidenced the initial emergence of Totally Drug Resistant TB cases in Italy, Iran and India.¹⁵

However, most people exposed to TB do not develop disease. One can assume that their bodies mount a sufficient immune response so that the proliferation of bacteria is limited. In most cases, this *partial* immune response will lead to a long-lasting partial immunity for the individual. Partial immunity means that further infection will *most likely* not occur, and that any latent bacilli from the initial infection will remain inactive (Smith and Moss 1994 ci Bloom 1994). An individual who is administered a Mantoux¹⁶ tuberculin skin test will react because their body still ‘contains’ latent TB bacilli (ibid). This is not to say that those who have had TB in the past will never become re-infected. Re-infection is often attributed to a suppressed or weakened immune system, one’s body is not strong enough to eradicate the bacterial infection. An important point to make here is that adults, whether they are infected through a primary infection, a re-infection or a reactivation, are smear positive in 50% of cases (Styblo 1984). It is these cases that are the main source of disease in the population, the community and the family unit (Shaw and Wynn-Williams 1954). It is therefore absolutely vital to identify those who unknowingly are potentially smear positive (infectious) because they will potentially infect others (Styblo 1984). The other aspect to consider is the availability and efficacy of treatment available. Before chemotherapy was introduced on a widespread scale, two different studies produced similar findings. In Britain (Springett 1971) and in India, the

¹⁵ See Udwadia et al (2007), ‘Anti-tuberculosis drug resistance in the world: fourth global report. The World Health Organization (WHO)/International Union Against Tuberculosis and Lung Disease (IUATLD) Global Project on Anti-tuberculosis Drug Resistance Surveillance 2002–2007, Schaaf and Zumla (2009), Velayati et al (2009), and Bhargava et al (2011).

¹⁶ Refers to the skin test developed by Frenchman Charles Mantoux in the 1930’s, where immunity to TB is tested through injecting tuberculin into the skin. Diameter is measured of raised skin area if a reaction occurs.

‘Madras Study’ (National Tuberculosis Institute, 1974) found that 50% of sputum-positive patients ‘died within 5 years of diagnosis, 30% “self-cured”, and the remaining 20% remained alive’ (Smith and Moss 1994:51). TB infection and treatment can be complicated in adult patients, but TB in paediatric patients presents its own set of unique circumstances.

Paediatric TB: Figuration 2

‘Because of the difficulty of confirming the diagnosis, the global burden of childhood tuberculosis in the world is unclear.’ (Kabra et al 2004: 387)

Children do not transmit TB but are vulnerable to infection, meaning they contract the illness from adults (Kabra 2004, Schaaf et al 2003). Children are more susceptible to various strains of TB because they have weaker immune systems, lacking the antibodies adults possess due to age and exposure to illness (Feja & Saiman 2005). In comparison to adults, TB symptoms manifest differently in children, and also shift depending on which type of TB they have. In adults, TB infection is generally characterised by night sweats, loss of appetite, weight loss, constant coughing and fevers. The symptoms in children may be less visible and are often overlooked. For example, constant vomiting and headaches are indicative that a child is experiencing the stomach flu; but they also indicate potential Meningal TB infection. TB-M, if gone undiagnosed and untreated, can result in spastic paralysis, neural damage, brain damage and reliance on a gastro feeding tube for the duration of one’s life. Missed opportunities, a less than vigilant health professional, or a complete non diagnosis often render tragic consequences for children and their families.

In addition, current paediatric research demonstrates that childhood TB is difficult to diagnose as there is no ‘gold standard’.¹⁷ Its global epidemiology has been poorly documented (Kabra 2004, Feja & Saiman 2005, Marais et al 2005, Marais & Pai 2007). Epidemiological statistics gloss over children’s presence in the TB epidemic; they are recognised minutely, however statistics largely render them a ‘forgotten’ category. These patterns remain, despite the continued call for more emphasis to be placed on children as patients, statistical and social markers and as a ‘vulnerable’ population. Walls and Shingadia remarked that, ‘...the rates of TB in children are unknown. This is an epidemic that, in most of the world, is spreading

¹⁷ *Pers comm.*

unnoticed' (2004:13). In the Western Cape Province of South Africa, 'children under 15 years of age form between 15% and 20% of this TB burden' (Soeters et al 2005:602).

For every person who becomes infected with TB, there is a TB 'contact' who doctors, nurses or social workers attempt to identify. This is not possible in all cases, but rather is an ideal scenario. The majority of the paediatric patients at BCH contracted TB from adult care givers, extended family or parents who had 'defaulted'¹⁸ on their medication, thus infecting their own children. Some, but not all, were infected before their TB contact was diagnosed or treated. Childhood TB prevalence can therefore be considered a 'barometer of TB control within a specific community' because children generally show symptoms within a year of exposure (Feja & Saiman 2005, Marais et al 2005:1310). This means that a community's health is evident in the health of its children; therefore, their treatment and those of their families is a high priority (Loeffler 2003, Kabra et al 2004, Walls & Shingadia 2004, Feja & Saiman 2005, Marais et al, 2005, Fairlie et al 2011).

Topography of Disease: Figuration 3

The complex layering and interaction of political systems, social bodies, historical precedence and individual movements enable the transmission of TB. South Africa exemplifies the interweaving of various historical processes which continue to this day via issues pertaining to housing, service delivery, transportation, education, labour unrest and inequities in health and health care services. The South African Apartheid government instituted a migrant labour system which effectively displaced millions, industrialised a nation, reaped benefit to the minority, and spawned multiple public health concerns; two of the most visible being the emergence of HIV and the persistence of Tuberculosis (Kark 1950, Packard 1989, Campbell and Williams 1997, Marks 2002). Tuberculosis incidence and prevalence persists within the mining industry, migrant worker, and prison populations within South Africa (Packard 1989). In addition, TB burden is still borne by the poorest of society living in the direst circumstances, globally.

In 1950 Stein recognised a positive correlation between poor housing conditions and TB. As Sheuya et al suggest, 'Most communicable diseases are associated with the conditions that

¹⁸ Term used in biomedicine describe cessation of treatment

characterize slums, and indeed, substandard housing in developed countries' (Sheuya et al. 2007; 2 ci Petersen 2010:16). Habib et al (2008) associated household overcrowding and poorly built houses with an increased risk of TB infection. Although substantial evidence highlights the correlation between inadequate housing, race, migration and TB (Veillers 1911, Stein 1950, Krieger & Higgins 2002, Sclar Garau and Carolini 2005, Strong et al 2005, Riley et al 2007), overall living conditions in South African cities have not improved dramatically since 1994. Nationally, many South Africans live in what is commonly referred to as 'informal housing', 'townships' or 'locations'. Houses are constructed of scrap materials: zinc metal sheeting, plastic, insulation, wood or metal scrap and plastic. Sanitation, basic service delivery and potable water are not universally accessible. Krieger and Higgins (2002) observed that healthy housing and better civic planning lead to healthier people. In many South African cities and *especially* in Cape Town, the architecture of Apartheid leaves its legacy in the health of its people. TB is a 'postal code' disease; those living in informal areas are disproportionately affected by where they live.

In 1949 Dr. Sidney Kark cautioned, 'The first line of treatment must be to remedy the unhealthy social relationships which have emerged as the inevitable result of masses of men leaving their homes every year...' (1949 ci Marks 2002:18). Unfortunately, the fundamental catalysts for TB transmission persist: overcrowding, poor nutrition, lack of education, poverty, migration and the daily struggle to survive¹⁹ (Farmer 1996, 1999, 2003). Simply stated, 'Tuberculosis is a social disease with medical implications' (Madalakas and Starke 2005:100). No other infectious disease has so thoroughly helped shape and been shaped by the contours of changing social, economic and political realities; TB is an old disease with contemporaneous implications.

Inequality and Urgency: Figuration 4

When DR-TB emerged in Tugela Ferry in the KwaZulu Natal Province of South Africa in 2006, 52 of the 53 patients reported died (Gandhi et al., 2006). Currently DR-TB affects populations in all regions worldwide (WHO 2013). TB is a disease of space; by way of airborne transmission it thrives in areas which are poorly ventilated, enclosed or overcrowded.

¹⁹Marais et al (2005) United Nations, The Millennium Development Goals Report 2005, Stop TB Partnership and World Health Organization. The global plan to stop TB 2006–2015 (2006), Tuberculosis Coalition for Technical Assistance (2006), Raviglione & Uplekar (2006). Global Plan to Stop TB 2012-2016.

Given the history of apartheid there exist huge social inequalities and class differences in South Africa. Social, economic, political and historical inequalities exacerbate adverse circumstances in health care accessibility (Farmer, 1996, 2005). South Africa has a highly politicised and publicised history of a co-existent HIV/AIDS epidemic. Many TB patients (although definitely not all) are also being treated for HIV. Patient non-adherence to TB drug regimens has also contributed to the spread of MDR-TB and XDR-TB. As Dye et al have noted, ‘Whatever the social, economic, and epidemiological context, TB control programmes rely on the health systems of which they are part’ (2010:861).

Central to the emergence of DR-TB, health officials started asking the question: how do we effectively ‘contain’ infected populations (Singh et al., 2007, London 2009, Harper 2010)? Ethical and human rights considerations are of paramount importance because involuntary patient isolation is an extremely contentious issue (Selgelid 2008, London 2009). Increased resistance to frontline TB drugs, inaccessible treatment options, migration, inadequate healthcare services, and patient ‘non adherence’ simultaneously spawned new forms of a curable disease, and generated multiple public health concerns, especially in urban areas²⁰. Government facilities were also cited for a poor response to the TB situation in South Africa contributing to these issue through inappropriate drug regimens administered to patients and incompetent medical staff (Padayatchi & Friedland 2007, MacPherson et al 2009). The migration of many health care workers (HCWs) from public to private sectors exponentially increased the demand and strain placed on those who remain within the public health sector. HCWs within government clinics and hospitals are generally under resourced and underfunded; a case of infinite needs coinciding with limited supply (Bateman 2006, 2007). The larger discourse surrounding DR- TB did not seek to address the *causes* of drug resistance, but rather, containment and isolation of those infected in order to protect the larger population of civilians. Multi-dimensional ethical questions resulted, weighing the pros and cons of individual human rights versus the public good in South Africa.

The South African Department of Health (SA DoH) currently favours a centralised approach to DR-TB treatment through voluntary isolation of patients who both test positive for DR

²⁰ See Farmer (1996, 1999, 2003), Bateman (2006), Padayatchi, Friedland (2007:1036), Singh et al. (2007), London(2009), Harper (2010), Streicher et al (2012).

strains and who experience treatment complications. If an individual tests positive for ‘normal’ TB, medicines are administered via the World Health Organisation (WHO)-recommended Directly Observed Therapy-Short Course (DOTS). DOTS was first conceptualised in the 1980s by Dr. Karel Styblo and then formally implemented as a pragmatic intervention by the WHO in the 1990s. In this treatment control strategy, the patient visits the closest clinic to their residence and takes their medicine under the direct supervision of a health professional. Patients are guaranteed a standardised treatment regime overseen by a health care worker for a minimum of the first two months of treatment. In addition they receive a regular drug supply and their details are captured within a standardised system of recording and assessment. Many of the patients have migrated from rural areas in search of employment find themselves newly diagnosed with TB, patronising city clinic services within this treatment model.

BCH was different to the DOTS strategy in that it was a facility that housed in-patients within specific wards to (literally) ‘contain’ and cure the disease. All of the patients I worked with were in-patients, meaning they lived at BCH throughout the course of their treatment. They were allowed to go home every other weekend on two conditions. One: their home life had to be assessed as ‘stable’ by the BCH social worker. Two: the child took their medicine without difficulty or complication. Child patients came from a variety of circumstances which in no way were homogenous. Generally, Brooklyn patients had extreme disease and came from troubled backgrounds. This manifested in various ways: previously defaulting on medication, abject poverty, were currently prisoners, lacked social support or could not provide for themselves. In-patients remained at the facility for the length of treatment duration²¹. Treatment duration (and ultimately treatment success) hinged on numerous factors and varied on an individual basis. Again, fundamental to these challenges was the need to identify those who may have potentially infected others unknowingly, or through defaulting on treatment. It is estimated that an infectious TB carrier may potentially infect 10-15 people annually (Falzon & Arıt-Belghiti 2007:1266, MacPherson et al 2009, WHO 2011).

The following section looks at the language around the social diagnosis of Tuberculosis. The story of TB is one which provides a rare opportunity to see the ways a disease has shaped the contours of language and in turn been shaped by language; especially metaphor. The social

²¹ Normal TB requires 6 months, MDR-TB requires a standardised treatment of 18 months, and XDR-TB 24 months-however this is not a strict guideline as other factors contribute to treatment adherence and success.

landscape of TB romanticised a little understood disease and further sentimentalised those who suffered from it. As David Morens observed, it would seem that ‘...scientific knowledge of the disease seems to have displaced our interest in the patient’ (2002:1354). This is an apt point given that currently one third of the global population is currently infected with different forms of TB and new drug resistant strains emerge almost annually. With such miserable statistics, how can one qualify the lived experience of TB, much less the faces behind one of the greatest killers in history? In a bid to reclaim the human component of the TB epidemic over time, a valuable starting point is to examine the metaphors which saturated and gave life to TB ‘culture’.

Consumed by Metaphor: The Social Diagnosis of TB

Kearns described metaphor as ‘...the application of words or idea to something which it is imaginatively but not literally applicable...’ (1998:271). Metaphorical language originated from the human desire to give meaning to illness and the experience thereof. As different metaphors emerge, societal attitudes also shift accordingly. The understanding of TB has evolved from a point of epidemiological and biological investigation to incorporating understandings of social stigma; however, the image of TB and TB sufferers has changed dramatically over time. Understandably, metaphors abound during circumstances of social, economic or political upheaval, and the continued presence of TB in human populations proved no different (Hanne 1996, Sontag 1978). Although metaphorical manifestations of TB often verge on the overly romanticised or poetic, Lakoff and Johnson (1980:5) noted that metaphor is pervasive in the everyday as a way of ‘...understanding and experiencing one kind of thing in terms of another’. In relation to TB, it is necessary to take inventory of these subtle nuances and their implications for those who are living with the disease.

‘TB is a disease of time; it speeds up life, highlights it, and spiritualizes it.’ (Sontag 1978:14)

Sontag’s observation demonstrates the deeply-seated poetic guise TB inherited through continued presence in human populations. Disease-related metaphors represented the prevailing values of different epochs. In the 19th century, TB was considered an all-consuming disease of passion and ‘inward burning’. A TB patient was deemed to possess more acute sensibilities: an enhanced emotional, creative and intellectual capacity. These qualities were

also seen as a precursor to contracting the illness. According to Sontag, the romantic images of the TB patient were the first widespread examples of a 'distinctively modern activity, promoting the self as an image' (1978: 29). Everyday descriptors became associated with those who had TB. Terms like 'Lungers', 'consumptives', 'health seekers' and 'tuberculars' represented this historical, categorical trend. The disease has often been described as 'the white death', 'consumption' and most recently, the 'monster' (Maxmen 2010). The employment of apocalyptic language continues to colour much of the TB social commentary since the co-prevalence and arrival of HIV (Upshur et al 2009). Again, language reflects prevailing social attitudes towards those who have TB, negatively shaping the disease and the afflicted patient.

Sontag was the most vocal critic of metaphors associated with illness, specifically cancer, TB and AIDS. She felt the person (patient) was stripped of their humanity and reduced to the disease (1978). Sontag argued against metaphor in her desire for illness to be 'just an illness', without negative associations attributed to the patient. In contrast, Susan DiGiacomo (1992) argued that metaphor is inevitable, and acts as a signifier which enables understanding. In response to Geertz's observation of the limits of ethnographic empathy, she writes, 'What we can legitimately claim to perceive is what others perceive with: the local categories and representations that constitute the common sense reality of everyday life' (1992:111). In this way, metaphors were an analytic tool to understand children's perceptions at BCH. Disease will never be reducible to a cellular level because disease is a social, individual and collectivised process: one which continually challenges an engaged medical anthropology.

Although Sontag's critique of disease-related metaphors was a salient project, it assumed a very specific patient group, and an even narrower definition of TB. Her evaluation was limited to the white TB patient of the Victorian era in Europe. In her understanding, TB was experienced on behalf of those white, city dwellers in western industrialised countries. She most certainly relied upon the literary imaginations of the time more than any 'real world' experiences. Her critique fell victim to the very metaphors she wished to dismantle; in this instance, fiction is stranger than reality. In addition, her desire for disease to be reducible to bio molecular and biological processes will forever remain unrealised because metaphors are significant nodes in understanding the disease and those who experience it first-hand. To eradicate metaphor is not only impossible, it forecloses on the human experience of suffering and ways that humans, whether patients or caretakers, make meaning from experience. In this

way, metaphors that patients employ provide valuable insight into arduous, if not life-changing circumstances.

Yet, the malleability of language, disease and body(ies) vacillates with the time and place from which they originate. In the United States for example (1880s-1940s), TB became a political and geographic agenda; one steeped in surveillance of the individual body and isolation of infection (Reynolds 2010). Americans with TB-like symptoms were oftentimes considered demented (Grineski et al 2006:604). Others who may not have been infected were enveloped into the fold, as TB had achieved catch-all status to describe chronic weight loss and persistent cough (Ott 1996). A positive TB diagnosis resulted in very specific social costs and as a result patients experienced the costs of social stigma (Abney 2010). TB patients were forced into isolation from urban areas, living alone without even the companionship of a domestic pet (Grineski et al 2006:604). 'TB was also added to a list of eugenic defects that could prohibit a couple from marrying. Similarly, married women with TB were told not to get pregnant' (Ott, 1996 ci Grineski et al *ibid*). The focus now shifts to the history of TB in South Africa.

The History of TB in South Africa

There is a dearth of historical information about the emergence of TB in Southern Africa prior to the 20th century, and the accounts provided emanate from missionaries and travellers. Reports of TB first appeared at the end of the eighteenth century, and were directly linked to contact with European colonists. The mining industry too played a pivotal role in the spread of TB (Packard 1989). South Africa as a 'health resort' mirrored the growing trend of the sanatoria movement in Europe. The dry, high altitude, warm 'climate cure' appealed to the many people who sought respite in the Cape. What emerged was a threefold contribution to the economy in the form of increased tubercular tourism, railroad development (fed by the mining companies) and a robust steam ship trade to transport potential patients. As South Africa became more urbanised with the discovery of gold and diamonds, city centres were filled with an influx of migrant labour. In the 1920s, the influx of worker populations far exceeded available housing, and living conditions deteriorated. In 1924, a doctor by the name of Peter Allen made the link between high mortality rates caused by TB and poor living conditions (Coovadia and Benatar 1991:27).

Many of the sanatoria in South Africa were guest farms which benefitted from the wealth of their overseas visitors. These types of institutions were established in places such as Beaufort West, the Karoo Desert, and Bloemfontein.

The Architecture of TB: The Sanatorium as Treatment Paradigm



Figure 2: Patients resting in BASF sanatorium for consumptives (1892) (Dannenfels, Germany) (Campbell 2005:483)

The ‘spatialisation’ of TB through the construction of TB sanatoria illustrates the social, political, economic, and health concerns in specific times and places. For the greater part of the 18th and 19th centuries, TB was woven into the social fabric of much of Europe and the Americas. As Craddock (1999) maintains, the production of bodies, disease and place are inseparable elements; sanatoria and preventoria exemplify these elements brilliantly. The sanatoria approach was (and is) not without controversy or critique (Harper 2005, 2010 London 2009). In the multiple mediations of the *best* and *most appropriate* treatment strategies available, scientific diets, warm places, the countryside, convalescence and sunshine factored high as depicted in Figure 2 above.

Sanatoria were first developed in Germany during the mid-19th century (Fairchild & Oppenheimer 1998). This model was based on isolation from the city and climate therapy. The original sanatoria reflect an ideology nuanced by the ‘natural’ and idyllic, as depicted in Figure 3 and Figure 4 on the following page. This ‘romanticised landscape’ (Cosgrove 2004) is one of remote, alpine bliss: replete with pine trees, crystal clear bodies of water and an abundant supply of fresh, crisp air. As early as 1898, physicians recognised South Africa’s climate as

ideal for TB treatment (Hillier 1898, 1899). This system of isolation arguably contributed to the linguistic, social, political and economic figurations of TB and by default, the TB patient. The intake of fresh, country air, graduated labour, convalescence, exposure to sunshine, exercise regimes, and healthy diet were integral to recovery of tuberculars (ibid). In Britain, the sanatorium emerged in the late 19th century because previously physicians had championed the ‘open-air’ method over isolation (Bryder 1988). However, not all sanatoria fulfilled this naturalist vision. Describing the sanatoria at the turn of the 19th century in New York, Rothman argued, ‘institutions...were too prisonlike to be hospitals and too hospital-like to be prisons’ (1992:72). Rothman’s observations are substantiated by Foucault’s (1973) early writings detailing the dualistic nature of surveillance and reform inherent in medical facilities.



Figure 3: Haus Caselva (1905), formerly Villa Merula, Davos, Switzerland (Author’s photograph, Campbell 2005:477).



Figure 4: Revolving two-patient hut (1909), in grounds of the City Hospital for Infectious Diseases, Edinburgh, Scotland, T.B. slides No. 101. (Lothian Health Services Archive, Special Collections Division, Edinburgh University Library.) (Campbell 2005:481)

Landscapes of Health and Hospital Ethnography

Mitch Rose suggests that [the landscape] 'is sustained not through something inherent within it but through the everyday practices and activities that surround it' (2002:456). The landscape here is one which *comes to be* and is *made meaningful* through the rhythms of those inhabiting it. Therapeutic landscapes have emerged within recent years as more than *places* of healing (Gesler 1992, 1998, 2004), but also places which promoted well-being and health (Williams 1998). According to Lakoff and Johnson (1980:29), the concept of a therapeutic landscape can be considered a 'container metaphor'. Situated sites of healing imply boundedness and clearly delineated borders; that which is not 'in' is necessarily 'out'. This presents a paradox in regard to BCH because not *all* healing can be considered to take place within an institution, denying the fluctuation of support from friends and relatives who may visit the individual patient.

Van der Geest and Finkler (2004) suggested that hospitals are often characterised as monolithic, biomedical entities which are globally uniform in structure and function (2004: 1995). Alternatively, they propose that, '...biomedicine, and the hospital as its foremost institution, is a domain where the core values and beliefs of a culture come into view' (2004:1996). This position mirrors that of other theorists (Lock & Scheper-Hughes, 1987, Feierman & Janzen 1992, Helman 2001). After the 18th century, hospitals evolved from welfare care centres for the poor, and became educational institutions (van der Geest and Finkler 2004: 1997). As Foucault observed, hospitals became places of instruction and surveillance, whilst patients became the foci of observation (1973).

Living within a hospital is often equated to living in a world separate from reality 'out there'. In a TB treatment facility, with its locked gates, security guards, buzzers, entrance and exit kiosks, one can feel very isolated from the routine of daily life. In contrast to this observation, hospital-based ethnographies shed light on how biomedicine is practised, but also how those who are the focus of healing feel about the procedures, tests, and routines they experience uniquely as patients. Schneider's (2001) work in China shows that there are intricate continuities between life *in* the hospital and life *outside* of it. A variety of authors (Tanassi, Gibson, Zaman 2003 ci Schneider 2001) support the claim that life within a hospital is far from being divorced from 'the real world'. Rather, hospital life is 'shaped by everyday society' (van der Geest and Finkler 2004:1998). Rosemary Blake's work (2009) with paediatric cancer

patients and their families also substantiates this point. Livingston's (2012) work in an oncology ward in Botswana is an exemplary ethnographic gesture. She explained:

‘Ethnographers recognise that the hospital is an intensive space where critical moral, political, and social questions arise regularly and with great urgency, and where broader political, social and moral forces in society can be witnessed in a condensed fashion’. (Livingston 2012:25).

Her observations are also shared by a small corpus of hospital-based ethnographic work²², most notably Mulemi's patient-centred research in a cancer ward in Kenya (2008).

‘Saving’ Children, Preventing TB



Figure 5: The Kellerberrin Preventorium (Grose 2011:98).

The concept of the *preventorium* emerged as an institution to protect vulnerable children in Australia (Connolly 2000, Grose 2011). The TB treatment became a biomedical mission encased by a larger social cause: to protect, and to rescue children from the ills of the city and society. The ‘natural’ landscape as ascribed and promoted by preventoria fit neatly with the ‘natural’ figuration of the child in 19th century discourse. The following quotes demonstrate some opinions of the time:

²² See Lock (2001), Kaufman (2005), and Rouse (2009)

One physician noted, ‘Children do better than adults as they will submit to discipline, they are unconscious of their danger, and have no worry’ (1923:343 ci Connolly 2000).

The same physician also recommended the following measures for paediatric TB cases:

‘Again, change of air is most desirable. And in my opinion (given sanatoriums under equal supervision) a patient should hardly stay longer than six months at one sanatorium. If a dozen children's sanatoriums were established in different parts of England, and the children (that is, pulmonary cases) moved every three or six months, I believe that such changes of air would shorten the two years' cure by at least six months.’ (1923:343, *ibid*)

In 1931, childhood TB specialist Dixon observed the differences in paediatric TB and that of adults. He wrote, ‘It follows, therefore, that the family as a whole, and not the (child) patient alone, should be the unit for investigation and continued supervision’ (Dixon 1931:637).

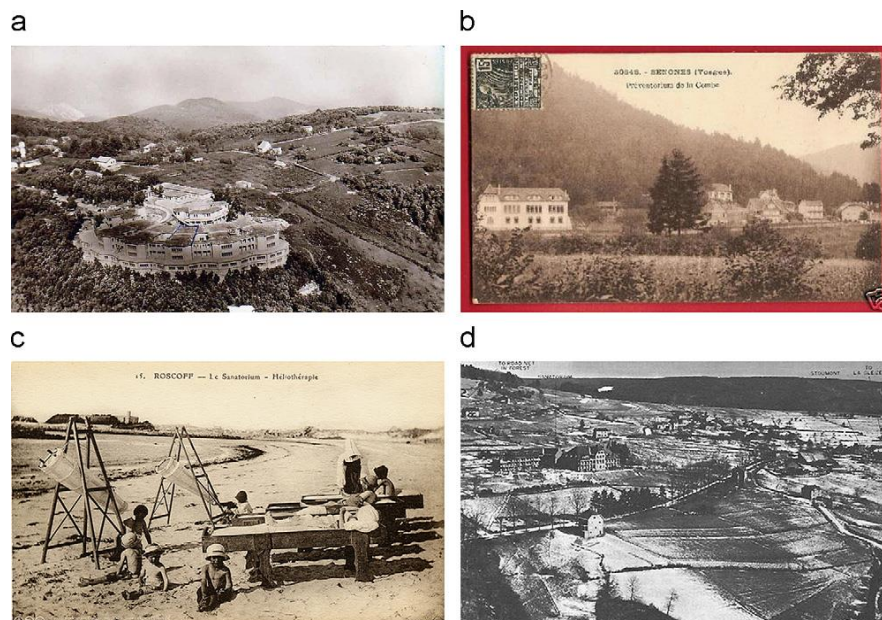


Figure 6: Postcards depicting preventoria as ‘healing landscapes’ situated in landscapes: beach, fields, mountains etc. Grose 2011:100).²³

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(a) Preventorium at Bugeaud, Algeria, http://encyclopedia.afn.org/images/8/81/Bugeaud_preventorium.jpg

(b) Préventorium de la Combe, Senones, Lorraine, France, Image is a postcard; date unknown.

(c) Préventorium de Laber—Annexe du Sanatorium Marinde Roscoff, Brittany, France. Vintage photographic postcard, circa 1925, published by Imp. Le Deley, Paris. Casas-Rodríguez Collection, 2009

(d) St. Edouard's Sanatorium for sick children with TB (off centre left) in the village of Stoumont, Liege, Belgium, (Cole, 2000:350 ci Grose 2011:100)

The Right to Write: The Historiography of TB

There has been extensive literature published on TB, but the majority of this body of knowledge stems from the health sciences and those writing under the rubric of medical history. However, given the abundance of scientific historical accounts there remains a dearth of anthropological literature which focuses specifically on those most affected by the disease, especially in Africa, and South Africa. The following section details the international TB literature, which concentrates on the United States and Great Britain. These accounts are framed within a 'science as authority' hegemonic voice, championing expert knowledge over the narratives of TB patients themselves. The following work attempts to bridge these gaps, and contribute to anthropological investigations within clinical spaces and paediatric patient experiences.

Lyle Cummins was a leading expert in TB research in the mid twentieth century, and assisted in enhancing medical understanding of the disease. His work, *Tuberculosis in History: from the 17th Century to our own Times* (1949), focused on the medical practitioners who worked in the TB industry. He wrote for biomedical practitioners and noted the progress achieved, highlighting significant contributions made by various clinicians. His style suggested a linear progression towards the eventual conquer of TB in infected populations. In 1953, Dubos and Dubos released their study *The White Plague: Tuberculosis, Man and Society*. This was a meaningful work because it marked the departure from an essentialised, purely biomedical understanding of TB. Their work provided a comprehensive overview of the disease including the political, social and economic components embedded in the emergence of TB. They provided multiple perspectives on TB and those living (and dying) with it, in addition to the social construction of disease via lay populations in westernised contexts. Dubos and Dubos initiated the dissection of socially constructed disease metaphors relating to TB. They also analysed how metaphorical language shaped the understanding of illness and the perception of TB patients. This in part paved the way for Sontag's influential work (1978) which I discuss in the following section. Dubos and Dubos' analysis was far more nuanced than that of Cummins' work (1949), however, it still relied upon the experience of white populations within the west.

Another influential, if not controversial, work was McKeown's *The Modern Rise of Population* (1979). Again, his focus was on Wales and Great Britain and the gradual decline of TB incidence from 1838 onwards experienced there. Like many of the previous works discussed,

the public health interventions in use during the pre-chemotherapy era were the largest discussion point, as opposed to social interventions to improve standard of living and preventative approaches to TB infection. The sustained dichotomy between these schools of thought continue throughout other historical accounts of TB, and do not radically shift until the mid-1990s. This, despite much advocacy for preventative measures in the form of social and economic reform.

Linda Bryder's work *Below the Magic Mountain* (1988) analysed the anti-TB campaign in Great Britain in the early 20th century. She, too, traced the pre-antibiotic era through political responses to TB leading up to the discovery of chemotherapy. Bryder also examined Britain's attempts at curtailing the spread of TB infection via the sanatoria movement, surgical interventions and public health safety campaigns. She concluded that sanatoria and treatment regimens were not effective in curbing TB mortality and infection. Unlike many of the previous theorists mentioned, Bryder consistently featured patient narratives throughout her work and explained that, '...a history of tuberculosis is not complete without considering the experience of those who contracted the disease, including the impact of the anti- tuberculosis campaign in their lives' (1988:3). Bryder, like the historians before her, failed to recognise the impact of TB outside industrialized nations.

In the 1990s and the first decade of the 21st century there was a renewed interest in TB. In 1993, Hardy published *The Epidemic Streets. Infectious Disease and the Rise of Preventative Medicine 1856-1900*. As the title implied, Hardy analysed the most prevalent infectious diseases of the time occurring in Britain, including TB, and compared the preventative public health campaigns attendant to each disease and its efficacy. Unlike the aforementioned theorists, Hardy focused on the sanitary approach to treatment and containment, thus suggesting that sanitary measures lent themselves to lowered TB mortality rates. Medical Anthropologists Marcia Inhorn and Peter Brown (1997) contributed to existing knowledge of infectious disease, and rightfully note that the emergence of AIDS and subsequent research endeavours have restored interest in TB. From the 1990s the historical literature starts to highlight the relationship between HIV/AIDS, TB and the social landscape of health and disparity. Again, these ideas were nothing new; doctors and social activists observed as early as the mid 1850's that TB was 'a social disease with medical implications'. With the arrival of the 1990s and the increase in AIDS deaths, TB came 'back onto the scene'. However it is pertinent to add, TB had never actually retreated in the first place.

In *Bargaining for Life* (1992), Barbara Bates recounted the history of TB in the United States during the pre-antibiotic era. The author focused on the relationships between medical health personnel, patients and care givers from 1876-1938. Similar to Bryder, the narratives provided originate in white middle class patients and their experiences with TB whilst living in different TB treatment facilities. She focused on the prominent TB physician of the era, Dr. Lawrence Flick, and his work with TB patients. Whereas Bates concluded that the sanatoria movement was largely insufficient and ineffective in meeting the demands of the TB epidemic, she recognised a few benefits that patients illustrated through their experiences. Patient narratives demonstrated that sanatorium living was accompanied by a sense of patient autonomy, relief from financial burdens and poor living environments, and nurturing relationships forged with medical personnel (1992:321).

In 1996, Katherine Ott published *Fevered Lives: Tuberculosis in American Culture since 1870*. Her work further strengthened the breadth of North American TB historiography. Ott provided an intersectional analysis of the social construction of illness, medicine, history and society. Ott's work was significant because it was the first to draw upon both medical anthropology and literary history. *Fevered Lives* (1996) emphasised the long-standing interaction between human populations and TB through rhetoric employed to describe these relationships over time. *Fevered Lives* critiqued contemporary reports and stated that as opposed to speaking about how 'Tuberculosis is back', it would be far more appropriate to state 'Tuberculosis is back in the news' (Ott 1996:157). She also emphasised that the rhetoric used was based on archaic 19th century discourse: 'medical authority conquers all disease' mentality. Ott's work documented a history of TB inclusive of attitudes and understandings, and how different understandings influenced ways of talking about TB. One such example is when Ott demonstrated how 'phthisis' became 'consumption', which eventually morphed into 'tuberculosis' (1996:1-2). This linguistic chronology charted the ways Americans signified the disease from 1870 onwards.

Ott's work stands in contrast to the previous works mentioned because her analysis benefits the South African context. *Fevered Lives* (1996) illustrated the negative assumptions and values socially associated to TB sufferers in North America. Immigrant populations, ethnic groups, minorities and those from lower economic classes were negatively aligned with the disease, thus emphasising the socially constructed meanings people attributed to TB sufferers. As TB references changed, so did the social meanings attached to TB. A parallel can be drawn

to the South African context where TB originated in white, European populations and eventually disseminated into impoverished populations, migrant labourers, and black South Africans.

Another work which contributed to the analysis of the South African context focused on the Firland sanatorium in Seattle during the pre-antibiotic, post-World War Two era. *Contagion and Confinement: Controlling Tuberculosis along Skid Road* (Lerner 1998) was a return to re-framing TB as a social disease. This work questioned the social and physical environment which impacted TB incidence and prevalence. Because Seattle, like Cape Town, had a high migrant labour population, the comparisons made are acute. Lerner critiqued the on-going debate between social and medical treatment efforts through his examination of coercive Skid Road facilities. Unlike the South African context, immigrants and transient workers were forcefully detained and isolated within these establishments until their schedule of medicine was complete. Again, the human rights discourse of individual rights versus the greater public good arose, yet in different contexts.

In *Tuberculosis the Greatest Story Never Told* (1992), Frank Ryan provided an overview of the leading medical practitioners, physicians and researchers who raced to 'find a cure' for TB. He included important dates in his detailed analysis of the mini epidemics which had 're-emerged' in Paris, New York City and other 'modern' cities. Undoubtedly, his work was an important contribution to medical history, yet, it too evoked the traditional (medical historical) format based upon a hegemonic, westernised, biomedical focus. The doctors and physicians mentioned are all white, of European descent and almost exclusively male. Given that Cape Town is considered not only a 'world class city', but also a TB 'hot spot', it is strange that Africa or even South Africa were not considered within this analysis. Again, there is a tendency towards a 'temporal hiccup', framing TB as a disease which appears and disappears; a non-cognisance of the continued presence despite what Kilpatrick (2002) referred to as 'public amnesia'.

Another assessment of TB with a specific demographic focus was Johnston's *The Modern Epidemic: A History of Tuberculosis in Japan* (1995). The 'public amnesia' of the disease occurred after TB incidence dropped dramatically post-World War II. Johnston's work detailed the decline of TB in Japan, but when it is applied to the South African context, there are astounding parallels in relationship to collective memory, and the ways people speak about

disease. During Apartheid, the infected populace shifted from white Europeans to predominantly black South Africans. Given the infrastructure (and overt objectives) of Apartheid governance, the medical needs of miners were not a top priority. Many were repatriated to the homelands, and many white people ignored the presence of TB because it no longer affected them on a daily basis and it was not a part of their lives, thus aiding in this 'public amnesia' featured in Kilpatrick's work (2002:24).

In *Consumed in the City: Observing Tuberculosis at Century's End* (2002), Paul Draus provided a sophisticated exploration of TB in New York City during the late 1990s. Drawing upon his public health care experiences, the work successfully incorporated ethnographic perspective within public health. Draus depicted the social challenges related to TB through ethnography. Draus was a public health care worker and his participants come from impoverished backgrounds: immigrants, welfare recipients, alcoholics, drug users, sex workers, and single-parent households struggling to make ends meet. This work was a distant cry from lauding the accomplishments of white European male clinicians. Rather, Draus questioned the efficacy of treatment and the realities of living in inner city New York. Through a political economy lens, Draus illustrated that TB treatment success largely hinged on social issues often beyond the individual patient's control. He concluded that it is impossible to treat TB without treating the social inequities and disparities which underlie the disease, a sentiment shared by humanitarian academics like Paul Farmer (1996, 2003). Unlike other works previously mentioned, there was a humanitarian thrust at the heart of Draus' work, once again presenting TB as a timeless, cyclical, social disease. Draus also alluded to the postulate that perhaps there is little to celebrate even in light of new technology, drugs or diagnostics.

A more recent publication, *The Ailing City* (Armus 2011), drew on extensive sources - oral history, media, literature, statistical information, the arts and medical journals - to illustrate how TB became a national narrative in Buenos Aires, Argentina from 1870-1950. Armus' intent was not to provide a comparative study, but rather to emphasise the similarities between other countries and major cities which experienced rapid industrialisation, economic change, labour and population influx, and TB. Unlike the aforementioned theorists, Armus dedicated a chapter to the figure of the child. He analysed the assumption that children were predisposed to TB and the impact this supposition had on public health care programmes and preventative measures. Most significantly however, Armus' writing highlighted that despite the roll out of new treatments, public health campaigns and new medical knowledge, the majority of those

afflicted with TB were not able to access these measures, nor were the implemented programmes sufficient to cope with seemingly endless demand. Therefore, the history of TB in Buenos Aires is strikingly similar to that of Cape Town, and potentially other areas in the Global South. It was, and continues to be, a story which is timeless: the never-ending cycle of infinite need and demand for treatment, limited supply of appropriate health care services and social resources.

Lastly, Helen Bynum's *Spitting Blood: The History of Tuberculosis* (2012), provides a sweeping and exhaustive historical account of TB and its relationship to humankind. Bynum traced its existence from ancient Greece into the contemporary moment. Bynum weaves together political and economic processes; industrialisation, world wars, urban poverty and public health campaigns in a bid to provide a comprehensive understanding of the emergence and re-emergence of TB. Her message is cautionary because TB remains an epidemic disease in many parts of the world, and one which is still being treated with drugs developed in the middle of the 20th century. Unlike other texts, Bynum acknowledges that as the 'conquest of TB' came to a prematurely triumphant end in the developed world, (thus slipping from public memory and public health campaigns), the incidence and burden of TB increased in other parts of the developing world. With the arrival of HIV/AIDS, the disease cycled back into public consciousness in places like New York City as an opportunistic infection. Her work is a call to activism, thus prioritising TB as an ever present infectious threat to human health globally.

Writing from the Local

Again, the ethnographic work from South Africa has been sparse, and is dominated by the confluence of primarily North American and British studies and historiographies. It is pertinent to note that medical anthropology has only briefly touched on some of the possibilities for TB as a stable area of inquiry in South Africa, and the literature available focuses heavily on the political economy of disease.²⁴ Again, this thesis contributes to the experience of TB from the perspective of children and hospital staff in an inpatient treatment facility and seeks to expand the growing corpus of hospital ethnography amidst a social, economic and political landscape specific to South Africa.

²⁴ See Marks and Rathbone (1982) for a good example.

Packard's *White Plague, Black Labour* (1989) is rightly heralded as the most important contribution to the knowledge and history of TB in South Africa. An American writer, Packard focused on the migrant labour system, mining and miner's health in the Gauteng Province. Whereas his approach was politically economy driven, what resulted was a thorough analysis which detailed South Africa's TB epidemic and the unevenness of TB burden. Packard associated the perpetuation of TB in poverty-stricken populations with the intensity of industrialisation, however his study remained limited to the Johannesburg area and surrounds due to the mining focus. It is pertinent to note that as of yet, there has not been a work as influential in the context of Africa or South Africa in relation to Tuberculosis.

A Century of Tuberculosis (Coovadia & Benatar 1991) was a multi-author edited volume aimed at bringing together perspectives from different fields on the topic of TB. During the time of publication, South Africa was undergoing a radical change in government in a bid for a new democratic South Africa and Nelson Mandela had just been released from prison. The collected works included epidemiological information, historiography of TB, connections to migrant labour and incidence and discussions on different types of TB. The authors rightfully acknowledge that, '...the contours of health and disease have rarely been as profoundly shaped by social and political realities anywhere, as they have been in this country' (ibid: i). Unfortunately the volume does not include any anthropological studies which would enrich the scope of their inquiry. Rather, the numerous TB case studies presented are sanitised through dependence on statistics and biomedical language. Without inclusion of individual narratives, there is no 'face' to the TB epidemic and history described.

Fiona Kilpatrick's work (2002), although a historical thesis, focused on the Chapel Street Clinic in Cape Town. In this work, Kilpatrick discussed the history of the Cape Town City Council's efforts to manage TB through the efforts of the Chapel Street Clinic. Thus, the localised context is set within an international historiography to provide a larger theoretical framework. Kilpatrick too relied upon the medical response to curbing the disease in Cape Town and the various public health initiatives of the period. Largely missing are the stories and histories of individual patients and their families. Although black South Africans were the most affected by TB during this time period, Kilpatrick focused on those from administrative and governmental positions during the Apartheid regime. It is no coincidence that the narrative is dominated by those who benefitted the most from the political institution; thus history provided is also a by-product of white privilege.

When Bodies Remember (Fassin 2007) focused on the historical imprint on the political present in South Africa: lack of access to treatment, governmental and institutional denialism. Whereas Fassin, a medical anthropologist, concentrated primarily on HIV/AIDS and its effects through the narratives of patients and their families in South Africa, he provided some insight into the TB epidemic. The analysis of TB incidence in South Africa draws on Packard's work (1989) and the social and political commodification of bodies; in this case migrant labour and the mining industry. As Packard asserted, at the beginning of the 20th century, the mining industry was deeply invested in trying to protect their labour pool from infection, because a decrease in available labour would adversely affect production. Varying hypotheses as to why TB was more rampant in black populations than white populations relied heavily on 'cultural' explanations which exoticized black Africans as being 'natural' or 'closer to nature' (Fassin 2007: 139). With the influx of black labourers into cities, they were unaccustomed to city life and the 'proper' way to live. Varying examples included wearing damp, or sweaty clothing which had not been dried sufficiently (ibid). This theory replaced others like the 'virgin soil' hypotheses which posited lack of immunity resulting in increased vulnerability to TB.

In the second decade another theory was put forward, one suggesting that susceptibility was inherited. Therefore exposure to tuberculosis was something that was contingent on natural selection and gradual exposure to the disease. This was a convenient enough (if not criminal) explanation for those in the mining administration, and allowed them to hire workers for months on end, only to send them home for 'rest' when they appeared infected. Fassin's point was this: although the 'native' body was the primary object of concern, the health of Africans was not what was *at stake*. Medical screenings, slum clearance, and segregation were implemented in order *to protect white populations*. Environmental and social factors were replaced by 'cultural', racial, or biological explanations. Fassin accurately correlated the co-presence of AIDS as an epidemic in South Africa, but also explained the historical precedence of TB long before the arrival of AIDS. As it was in the past, so it continues to be here in South Africa. Recently, Minister of Health Dr. Aaron Motaaleli called upon the mining industry and prison system to provide more efficient case recognition and provision of medicines to those identified as tubercular. The strength of *When Bodies Remember* is not just its eloquence, but the power Fassin brought to the narratives of patients and their families as a cautionary reminder of the lessons history can teach.

Thus far I have established how TB and children have been figured in different ways, in different epochs. As society changed, conceptions and responses fluctuated accordingly. This work demonstrates the different figurations of children, TB and understandings of time within a hospital environment. I investigate these varying figurations: imperfect and episodic, not as permanent or fixed, but merely as flashes of interaction, agreement and contestation. These figurations build on the larger discourse presented in this introduction and will continue to figure into a broader engagement with TB, history and society.

Thesis outlook

The following chapter discusses the methodological limitations and ethical considerations throughout the fieldwork process. In contrast to the figuration of the child as an *ideal participant*, much of the research required a reconceptualization of the ethnographic tool kit. Most of my research participants wanted to participate on their own terms, and in their own way. ‘Traditional’ qualitative methods were not useful for these ‘non-participants’. One of the main arguments put forth in chapter 2 is that non-participation should not be viewed in a negative light. Often in child-centred literature which focuses on methods with child research participants, non-participants are edited out of the final research product. I also problematise the language which pervades most of child studies literature and reflect on the impact on methodologies used (or not) in the fieldwork process.

Chapters 3, 4 and 5 introduce the actors who helped animate one year in the life of a hospital. While child-focused, this thesis is not solely about working with children in a clinical environment. The relationships forged between teachers, nurses, doctors and overseas volunteers help to describe and give shape to various forms of care experienced by child patients. These relationships; between practitioner and patient, nurse and teacher, child and volunteer breathe life into Brooklyn as a thoroughly social, but also clinical space. Chapter 3 introduces the processes which indoctrinated children into the role of paediatric or child patient within the hospital. Doctors and nurses cyclically figured the paediatric patient with every new admission; however the homogenizing processes and tasks of biomedicine are not without exception, loopholes or flaws. Although myriad actors and processes are involved in figuring the child patient, thick bureaucracies, diverse care practices and uncertainty penetrated BCH. Nurses, doctors and children themselves grappled with the entanglements of sluggish bureaucracy, and rigid routine, thus lending to the social life of a hospital. Nonetheless, a specific, regimented ‘patient lifestyle’ is constructed with the understanding that patients must

conform, take their pills and abide by these powerful protocols and biomedical rituals. Visual ethnographic material produced by children is presented to help elucidate the ways children embodied life in Ward 3 and the space of Brooklyn Chest as patients.

Chapter 4 considers pedagogy at the fringe: the productive chaos of a school that is both (paradoxically) a school and *not* a school. Teachers explained the challenges of a hospital school that is not registered, yet simultaneously acts as a pivotal interface for the BCH teachers, their new students and the continuity of life ‘on the outside’ whilst being a patient at BCH. The hospital school, and the teachers employed there, acted as an anchor of support, care and encouragement. Attending school daily helped to provide stability and consistency for child patients, which was oftentimes lacking in their ‘home’ school. Children within the school were figured very differently because they fulfilled the additional role of student. Their personalities were disambiguated, their hopes, fears and personal circumstances were brought to the fore in a way different than within Ward 3

In Chapter 5, the phenomena of service education tourism touches down at BCH. Overseas volunteers brought with them baggage which did not seem to fit within the confines of a suitcase: personal philosophies of paternalism packaged within good intentions, ‘white guilt’, and civilizing missions. Through interviews and conversations, I explored volunteer intentions through their work at BCH in addition to their motivations for working with ‘sick children’. Here, Brooklyn is simultaneously being created as a space for education and service, of care and tourism. Five volunteers reflected on their time spent at BCH and their imaginings of Africa, their figuration of the ‘vulnerable child’ and their pre conceptions and ideas of working with paediatric patients in a hospital environment. Although temporary fixtures in the hospital, volunteers and their interactions with children influenced patients’ views of foreign visitors and their intentions of working in Africa, thus contributing to a landscape of care in the hospital.

Chapter 6 discusses the malleability, significance and the detrimental effects of time in patient narratives and the use of time as a metaphor. These perspectives lend themselves to filling the gaps in the history and the re-telling of TB because time is crucial to the lived experience of illness. Time references were used by children and hospital staff, metaphorical associations helped convey multiple messages. Time became a way to speak to burden, anxiety, pain and ‘not-knowing’. Time, and the ways people speak to time, gently contest the stringency of

biomedical temporality and Sontag's (1978) desire for the understanding of disease to remain sanitised within a biomedical explanation. Disease cannot be stripped of its social underpinnings, exoskeleton or substance. Diseases may manifest in a biological manner which is identifiable through various biotechnologies, but the entire experience of disease is thoroughly grounded in social processes, relationships and experience. At every level, those who treat tuberculosis, those affected by it and infected with it give meaning and dimension to the experience of living with the disease. Although treatment contexts and healing spaces may vary both locally and globally, it is the social experience imbricated with the biological manifestation of TB that create, question, and ultimately remake our understandings of this timeless infectious disease.

Ethics and Methods: The Limits of Mutuality

I arrive in the morning and they are lined up behind the fence screaming my name – jumping, laughing and very excited. We go to school and they are bouncing off the walls with seemingly endless energy. The children fight, play, they taunt each other and show compassion. Their resilience is striking. However, I am constantly reminded by the nurses and teachers that they are very sick. Their health feels like a constant guessing game. (Field notes)

Xoli is having issues with her amikacin injections. The injections are dreaded; the insertion creates welts that bleed and are very sore. They are extremely painful, and I wonder if any of the children ever really ‘adjust’ to them. She squirms and we try to restrain her gently enough to get the syringe ‘in’. I am helping as the nurse depresses the syringe into her bum. She squirms and flails to the point she must be released because we are worried she is going to prick someone or damage herself. She sits and screams for her mother. Nurse June is sympathetic, Nurse Jones rolls her eyes and says ‘Stop crying child!’ Xoli sits and screams and cries, and I don’t know what to do. I pick her up and she hangs on so tight there are marks on my arms afterwards. I didn’t know what else to do, I couldn’t ignore her, I was following my intuition. (Field notes)

Luto is going home today, and I feel very sad. We had so little time together. He’s 15 but looks more like a 10 year old. He has lived in a very sheltered environment for the past two years – with the same faces and friends going to school and living together every day. Understandably, it will take time for him to adjust. He just keeps telling me how much he loves me and will miss me. ‘I’m going home today’ he says. I think about the challenges – at home, at school...will he ever be 100%? Will other students bully him? So many unknowns. (Field notes)

The above excerpts were from the first month of fieldwork. Moments such as these duplicated themselves through acts of care: persuading children to take their medication, ‘being there’ for them when they felt nauseous or comforting them when they missed their parents or caregivers. I had difficulty adjusting to these everyday routines. Outside of BCH I was haunted by nightmares, insomnia, and paranoia. While the nightmares signalled my immersion in the ever changing dynamics at BCH, the insomnia and paranoia stemmed from multi-pronged fear. Fear of contracting TB, fear for the children and their well-being, and fear of death, but not my own. In the year of research at BCH I was constantly sick. Seasonal flus, ‘colds’ and a particularly bad case of hay fever punctuated parts of the research. When I felt unwell, I had to stay away from BCH because I did not want to expose the children. One entry reads:

I feel terrible today. Persistent coughing, phlegm of all different colours and textures. My body feels like it is on fire. I feel so guilty about not going in (to BCH), but I don’t want them (the children) to get more sick. More bad dreams last night. Luminescent purple bacteria crawling from inside my lung cavities, eating me from the inside out. (Field notes)

In no way can one compare episodic bouts of illness to children's' experiences of TB infection; rather, these thoughts demonstrated the mutually constitutive nature of fieldwork. When I was sick, I received text messages to inquire after my health, and detailed chest examinations from children (especially if I was coughing). In one instance when my car was being serviced, a child asked me, 'Is your car sick like us?'

My dilemmas in fieldwork highlighted the larger confrontations anthropologists face when trying to capture, and ultimately interpret, the worlds of those they work with. Although anthropology continues to strive to translate the social suffering of others²⁵, the perennial question remains: how can anthropologists legitimately offer reflections, when our analysis remains forever locked in interpretation? What are the limits of mutuality when working with patients hospitalised with debilitating, often chronic disease? How do these realities affect ethical engagement and ultimately the methods utilised in ethnographic clinical research?

Pina-Cabral offered the following thought:

'More than that, however, the traditional propensity of anthropology towards semiotic models of interaction, where conscious meaning is treated as the be-all and end-all of communication, has presently given way to more sophisticated understandings of the fieldwork context. We must find ways of approaching analytically the ethnographic gesture that do not disembodify it; that preserve its physicality in a world where *what we understand is as much communicated by others as it is understood with others*. We participate jointly in environments that are historically inscribed with sociality.' (2013:258-259, emphasis mine)

Therefore, the limits of mutuality were an ever-present hallmark of my research with TB patients: adult or child. The challenges were many, especially when attempting to understand the complexities of life, but also, *a life made more complicated* by TB when the primary investigator did not *have* TB.

The chapter details the ethical considerations and the methods employed in the research at BCH. Firstly, I examine the language used in childhood and child participant studies. Language helps shape not only the theoretical terrain we as anthropologists and social science researchers strive to question and develop further, but can also impair further theoretical and

²⁵ See Kleinmann (1988), Farmer (1996, 1999, 2003), Kleinmann, Das, & Lock (1997), Scheper-Hughes (2003).

methodological insight. The chapter concentrates on three main ethical issues which arose in research, but specifically within a clinical space. Informed consent, confidentiality, and power dynamics were three major themes that, while not unique to research with children or adults, set against the clinical backdrop of BCH was made more challenging. The third portion of the chapter considers the ways ethical issues shaped the methodologies employed during research. Lastly, I introduce the children I worked with through moments of realised ‘methodological mutuality’ (Pina-Cabral 2013). Methodologies are analysed from both the perspective of child participants and those who chose *not* to participate in many of the activities on offer. In choosing non-participation, a child exercised their individual ability to make their own choices, on their own terms. The turn of phrase ‘methodological mutuality’ infers an agreement, but one prompted by the child participant themselves (and generally to reject a method I suggested).

Non-participation should not be viewed negatively; rather, the data demonstrates that it created new dialogues about ‘child-centred’ methodologies and ‘agency’. Non-participation has not been a major foci of investigation with children and research. Rather, the literature available focuses almost exclusively on what methods ‘work’, not those which ‘fail’. Attenuation to children’s perspectives on *methodological malfunctions* lend themselves to developing better research instruments, creating a more robust theorisation of children’s voice in general, thus problematizing the often used, but under scrutinised term, agency.

Moreover, language in child-oriented research often portrays ‘ideal’ research participants. The ideal participant is one who enthusiastically participates in a variety of activities, and without hesitation, thus exercising ‘agency’. A heavy dependence on the terminology researchers utilise misrepresents childhood theorists’ corpus of work, the challenges they face, and the inherent (and ever-present) issues of representation. Voice and representation are two ongoing themes and challenges in anthropology. The language used in depiction must be accurate, whilst simultaneously descriptive of those involved and the processes at play.

Language of the Child

Over the past three decades, there has been increased interest in research *with* children, as opposed to *on* children (Christensen and James 2009). This paradigm shift has been met with increased recognition of children’s rights as well as the reframing of research with children in the social sciences (Schwartzman 2001). Other trends mark the engagement of children or the

employment of children as to encourage research *by* or *led by* children (Young and Barret 2001, Das and Reynolds 2003, Alderson 2007). Through a reconceptualization of what possibilities lie in childhood studies, the social sciences have encountered old and new debates, as well as developed new methodologies with child participants.

Children are recognised as *active* ‘contributors’, ‘agents’ and ‘participants’ as opposed to merely *passive* vessels to be filled with new types of knowledge (Hardman 1973). While anthropologists grappled with children’s voice and representation of children’s lives (Jenks, 1992, Shaw 1996, Levine 2007), David Lancy (2009) argued that there has been significant work historically on children as active social agents and makers of their own worlds within anthropological accounts. These observations refute Hirschfield’s speculation that anthropologists ‘don’t like children’ (2002). The goal is not to discuss divergent debates or assumptions on whether or not children are able, willing, or capable enough to participate in research, because they most certainly are. In addition, the following chapter does not discuss the legitimacy of their accounts (Docherty and Sandelowski 1999, Punch 2002), as this is taken as an established starting point. Children’s worlds do not need to be purveyed or examined in conjecture to adult worlds, and who better to speak to about a child’s perspective than a child himself (Waksler, 1991, Jenks 1992, James et al 1998, Backett-Milburn 1999). As Shaw observed:

‘We must accept children’s world views as a legitimate, lived reality, and yet also accept the significance of the constant change and growing that occurs in childhood.’ (1996 ci Backett and Mckie 1999:389)

However, it is theoretically reckless to categorise children as miniature adults, and this, I fear, is something that occurs far too often in the ways children are represented in academic discourse. Castaneda’s (2002) work with the figuration of the child is a helpful guide in this regard. Castaneda asserted that children are always in the process of *becoming*, they are not an actuality, but a potentiality. She recognised that figurations of children are rooted in specific (if not unique) circumstances throughout history; her appraisal is refreshingly realistic, and lacks romanticised window-dressing. She theorises children as malleable entities, not rigid certainties. In response to Castaneda’s work Grinker explains:

‘Thus, the child never is an entity in and of itself, but always exists in the *service of some other subject*. The lack of children’s self-representations makes it all

the more difficult to conceive of an alternative figuration of the child’
(2004:856, emphasis mine).

Grinker’s assessment is apt, especially given the circumstances many children find themselves in at BCH. Their social backgrounds, admission to BCH, and the set of rules and newly acquired patient lifestyle they adhere to are not circumstances of their own making. They have been subjected to a series of events they have had (in most cases) no control over. Perhaps the aspiration of childhood theorists is to provide a new, romanticised conception of childhood(s) or the figure of the child; but frankly, children’s representations of themselves at ready hand are only available through the synthesis of research such as this. Grinker’s reflections segue neatly to the Slovenian philosopher Slavoj Žižek’s work *The Parallax View* (2006). Here, Žižek borrowed the extended metaphor from Japanese philosopher Kojin Karatani. He writes:

‘The standard definition of parallax is: the apparent displacement of an object (the shift of its position against a background), caused by a change in observational position that provides a new line of sight. The philosophical twist to be added, of course, is that the observed difference is not simply “subjective,” due to the fact that the same object which exists “out there” is seen from two different stances, or points of view. It is rather that, as Hegel would have put it, subject and object are inherently “mediated,” so that an “epistemological” shift in the subject’s point of view always reflects an “ontological” shift in the object itself. Or—to put it in Lacanese—the subject’s gaze is always already inscribed into the perceived object itself, in the guise of its “blind spot,” that which is “in the object more than the object itself,” the point from which the object itself returns the gaze. “Sure, the picture is in my eye, but I, I am also in the picture”’. (Žižek 2006:17)

Parallax, although a theory applicable to numerous subjects from astronomy and physics to developing more accurate observational instruments, fundamentally affects the way human eyes perceive the world around them. Human eyes perceive different viewpoints of the world (or an object) simultaneously through the process of stereopsis. Simply put, our brains are capable of assessing depth perception and the distance to objects at the same time. Parallax then, is to see the reality produced from the perspective of difference: neither the object nor the subject, but the blind spot. The angle of viewing essentially alters the perspective from the standpoint of the observer, but also skews the overall observation. When applied to ‘children’ or ‘paediatric TB’ as observational points, the larger discourse or representation of TB is obscured. Thus, parallax is a more effective way to critically enhance a growing theorisation around children and childhood; a focus on children necessitates recognition that children do

not make their own worlds independently from those of adults. Conversely, adults help sculpt and mould the worlds of children. This could not be more relevant than in the hospital world of BCH.

A *parallax view* then, to borrow the term from Žižek, allows space for the blind spots, the mutually constituted moments between child and adult, championing neither perspective over the other, while maintaining the messiness of perspective and the diversity of observations. Striving for a purified representation of children is not only over-sentimentalised but, I believe, unattainable. As theorists who work with children, honest jargon-free language wilfully reflects practice.

Inverting Child-Centeredness and Agency: The Problem with Language

In a recent work, Hunleth (2011) problematise the language of children's studies and the ongoing issues with representation and voice in the social sciences.

‘If we cannot avoid issues of representation, then we must develop a more nuanced understanding of what research *with* instead of *on* children really means. This is not a suggestion to abandon the basic ideas behind research with children and the view of children as competent research participants.’
(Hunleth 2011:83).

Hunleth's reservations are significant, because language provides fundamental shape to ethical underpinnings, and subsequently, the methodologies employed. Hunleth's work inverts the question of what methods are most efficacious for the researcher. What does it mean to employ child-centred or child-oriented methodologies? How do children make meaning out of methods suggested or implemented by adults? To invert the question of what child-oriented research means is to think through what makes particular methods more effective for the researcher, not just for the children participating in the research. Phrases like ‘child-led’ or ‘child-oriented’ have now become emblematic of ‘good’ research: for *really* hearing children's perspectives and somehow enabling agentic forces (Hunleth 2011). Gallacher and Gallagher (2008) take this analysis one step further and flag the notion of ‘participation’ as problematic. Participation, in their opinion, assumes a direct correlation between being ‘active’, and ‘empowerment’ of children to become active within research. Inactive participants are therefore positioned as uninvolved, and most likely in the final research product, dismissed.

The following chapter starts to address working with ‘inactive’ participants. In this assertion, ‘inactive’ participants are those who refuse to take part in group activities, but prefer to interact with the researcher on a more personal, one-on-one basis. Inactive or alternative participation is *still* participation, but does not fit into the dichotomous model of inactive/active participation. Is this not the type of nuance Hunleth urges theorists to consider? Or can we blankly assume that inactive participation is yet another case of an oxy-moronic phrase (oft-used and ill-conceived) like participant observation (van der Geest and Finkler 2004:1998)? A superficial application of this type of terminology further denies the heterogeneity of children and the varied experiences of childhood, and risks an over-sentimentalised, homogenous representation of childhood works. Additionally, it assumes that there are discrete research methods specific to working with children, as opposed to adults. James (2007) has refuted this notion. Given the ongoing issues of authenticity, voice and representation, she explains that social science research with children or adults are not discrete or radically dissimilar entities; they face the same set of challenges and inherent confounding variables. This sentiment is also shared by other authors, namely Harden et al (2000) Punch (2002) and Christensen (2004).²⁶

So then, do ‘child-centred’, ‘child-led’, or ‘child-friendly’ methodologies infer exclusivity to children, or does it assume that an activity is potentially *too* ‘child-like’ as Backett-Milburn and McKie (1999) suggest? This approach recognises that children can fulfil multiple roles, and at their discretion. Children are sometimes simultaneously decision makers, teachers, mediators and contributors. So then, what do ‘participation’ and ‘agency’ entail?

Embedded in these observations is that children exercise ‘agency’. Trawick provides one such definition: ‘...children exercise agency – they knowingly act on their worlds to change those worlds’ (Trawick 2007:5 cf Lancy 2012:2). Pole et al (1999) tune their definition to recognise constraints of agency:

‘Clearly, the degree to which any adult or child is able to realize his/her own agency is tempered by a wide range of factors such as social class, gender, ethnicity and age, alongside the prevailing political, economic and cultural ethos of the society in which he/she is located’. (ibid: 42)

Lancy is particularly critical of what he calls the ‘Agency Movement’ (2008, 2012). He cites many studies which employ the term haphazardly and without critical reflection. All of the

²⁶ For a comprehensive review of related literature see Kirk (2007).

examples Lancy critiques – and there are many – directly contradict the ‘agency label’ they so readily appropriate. In agreement with Lancy, agency *is* worthy of investigation, but not thoughtless appropriation. In a recent work (2012) Lancy lists eight postulates accompanied by examples where theorists incorrectly used the agency label. Of the eight ‘child agency problems’ Lancy details, there are two (agency is classist, agency is hegemonic) which particularly resonate with my research. In his discussion of child agency as classist, he cites Amartya Sen who notes, ‘an individual’s agency...is constrained by the social, political and economic opportunities that are available’ (Sen 1999: xi–xii ci Lancy 2012:8). Agency, therefore, is not something *freely available* to every child, and notions of agency will contrast starkly given the area one lives in, the structure of one’s family and parenting values engendered. Lancy specifically details the parenting model of child-play which is more prevalent in Europe and North America. He states:

‘There are numerous international programs, which promote this philosophy, and it is being vigorously exported outside the dominant society. In the rest of the world, of course, parents are rarely reported as playing with children.’
(Lancy 2012:8)

Those who chose not to conform to the play model relayed fears of their children growing up as egotistical, self-focused adults; rather, they opted to constrain their own child’s agency so that they would grow up with ‘better’ values. My findings demonstrate that individual agency is only manifested through resistance to participation, thus creating different possibilities voiced on behalf of child participants. Additionally, the agency ‘allowed’ is only within the structures of the adult-patient relationship; this type of agency is based upon power structures at BCH. In short, children are given instructions, and therefore space to conform (or not conform) to those directions. To be clear, the research does not argue that agency and its theoretical underpinnings are not useful; they have a different merit in my research, of which I shall demonstrate in the methodologies section.

Ethical Techniques

In the following sections, I discuss the ethical considerations and ethical dilemmas which emerged during the research process at BCH. Preliminary theoretical and hypothetical ethics considerations contrasted starkly with the ‘real’ ethical issues which emerged in the field. To clarify, ethical considerations are often abstracted through case studies and hypothetical scenarios; these remain intangible because there is a distance one maintains. Actual or *the real*

ethical events are made tangible through the interaction between myself and child participants. These events shifted an understanding of what it meant to be working in a space with children who have been entrusted to the care of others while they are very ill. Different events brought into harsh focus the reality and consequences of *actual* ethical violations first-hand. Simultaneously, my interactions with health care professionals and non-medical personnel helped to galvanise a broader understanding of ethical issues and how they were negotiated by different groups.

Ultimately, I found that while an understanding of ethics varied from child to child, there was a broad children's rights-based code which was reinforced by some medical staff and teachers. Some cited the United Nations Convention on the Rights of the Child (United Nations, 1989) and the 1989 Children's Act in the UK. The understanding and translation of children's rights differed amongst the aforementioned groups, and was evidenced in different ethical techniques. Ethical techniques describe different strategies employed by various BCH personnel to mediate a range of circumstances. Children negotiated their own understandings and ethical techniques in very specific, strategic ways. Ethical techniques helped to substantiate children as knowing contributors to research, but also reified their exercise of agency. In addition, children identified adults who were 'trustworthy', either individually or by group consensus. In more extreme situations wherein an adult had violated perceived children's rights, selected adults (including myself) were subsequently approached to help mediate breaches in ethical conduct, whilst simultaneously maintaining a relationship of trust with the child, or children. Therefore, trust was inextricably bound to an understanding of ethical conduct and ethical violations within the space of BCH. Drawing on a feminist ethic of care can widen and potentially add depth to the current discussion of child rights and ethical conduct within research.

Ethics of Care

'A feminist ethic of care begins with connection, theorized as primary and seen as fundamental in human life. People live in connection with one another; human lives are interwoven in a myriad of subtle and not so subtle ways. . . .' (Gilligan, 1998: 342)

Feminist ethics offers a philosophy appropriate to working in a hospital environment with children, and feminism has a long established ethics based on 'care' (Strathern 1985, Haraway 1988, Tronto 1993). Care in and of itself is based on looking after, attending to, or looking out

for the well-being of others and for oneself, while paying particular attention to the relational qualities herein. Anthropologists can agree that care is a central component of the ethnographic enterprise and often a fundamental motivation for research. Whereas in the past care work has been gendered, this should not be a limiting factor. As Tronto (1993) argued, an ethic of care is a general position and should not be identified with women solely. This point is perhaps even more salient when working with hospitalised children who are entrusted to the care of the institution. As anthropologists, we care through the practice of accompaniment; it is what we *do*. However, to theorise children as merely the recipients of care, or rights for that matter, is to deny other forms of care which arise in the specific context of BCH. In addition, ‘children as carers’ thematically has gained ground in sociological and anthropological works (Aldridge and Becker 1993, Aldridge 2012).

A feminist ethic of care provides different ways of theorizing every day context and the relational ethics involved in further understanding that *context and relationships matter*. Sole reliance on a rights-based approach when discussing ethics and children in research is potentially very limiting. To draw upon Žižek again, blind spots persist. As Cockburn (2005) pointed out, a claim to rights are always in a bid to possess *something* against *someone*. Furthermore, O’Neill (1988) argued that the rights discourse advances the reasoning that someone is laying claim to something they feel they are being dispossessed, or deprived of. Cockburn framed children’s rights within a feminist ethic of care framework to challenge the notion of children solely as recipients of care, and in doing so, opened up the possibilities for an expanded ethic of care (2005). He identified three major points based on Tronto’s work (1993) and in contrast to Gilligan’s ‘ethics of rights’ approach (1998):

‘An ethics of care 1) involves different moral concepts: emphasizing responsibilities and relationships rather than rules and rights. (2) It is bound to concrete situations rather than being abstract and informal. Morality is adjoined to social practices and customs, and to people’s feelings and opinions, and this is how good judgment can be realized. (3) The ethics of care can be described as a moral activity, the ‘activity of caring’, rather than a set of principles which can be followed.’ (2005:72-73)

Henderson (2004, 2011) and Ross’ (2010) notions of ethnographic accompaniment gesture toward caring as an activity, whilst simultaneously providing space for silence. Lastly, children are often subsumed as inherently vulnerable, which also diminishes the fact that human beings

(even adults) are, in general, at any given time both vulnerable and resilient, even in the face of adversity. Vulnerability may be episodic, but vulnerability remains inseparable from the human condition. In essence, shared vulnerability lends itself to the definition of the human condition and being able to recognise the vulnerability, suffering, or need in other human beings. Positing specific methods for ‘vulnerable populations’ (Aldridge 2012) is also unhelpful. I suggest the language around vulnerability and children must shift. Perhaps the language of vulnerability can be supplanted by dependency. Children are dependent on adults, and when care-giving structures are stripped from a familiar to an unfamiliar structure (BCH) and supplemented with new care-givers there are different dynamics at work. As a theorist, one cannot remove the vulnerability aspect from children, but we can change the way we speak about children, and dependency is a far more egalitarian lexical device.

A needs-based *obligation to care* which focuses on the parents, care-givers or adults in the situation heeds the social context and the web of relationships involved, but also identifies those who are more ‘in need’. This identification process is problematic as it positions someone or a body as the identifier and the other as the individual, or group in need. Institutionally speaking, a needs-based approach to care reflects characteristics of patriarchy and paternalism and is perhaps more emblematic of missionary work in less-developed countries in the 19th and 20th centuries.

The types and variations of relationships developed with the children at BCH grew in number over time. I did not have the same type of relationship with every child. My relationships with them as a group and individually vacillated in contrast to the types of relationship I had with specific children, the ever-shifting dynamics of the ward, and my (sometimes) strained relationships with adults in the ward. Oftentimes I was a keeper of secrets, a friend, a temporary enemy, a disciplinarian, a teacher, or was referred to as ‘mama’, *titi*²⁷ or big sister. An essential starting point to accompaniment is to reflect on personal positionality: the ways I was perceived within a new environment, and the ways in which I presented myself.

Power Dynamics

It is widely acknowledged in anthropology that consent in a research relationship must be facilitated and enforced on a regular basis, and that obtaining consent is an on-going process.

²⁷ ‘Sister’ in Afrikaans

In addition, research within a clinical environment presents specific ethical and methodological challenges. In some hospital-based fieldwork, researchers assumed authoritative roles, visually emulating doctors through wearing the 'white coat' (Weiss 1993, Gibson 2004, van der Geest and Finkler 2004). This approach is covert and inappropriate within ethnographic fieldwork. Children were extremely aware of the power hierarchy of the hospital, and developed trust very slowly. Wearing a white coat or assuming a false identity is in and of itself unethical. In contrast, Bluebond-Langer's (1978) approach as a long term visitor is a useful position to assume, and I tried to replicate that in my interactions with children and their families. In her research with terminally ill children, Bluebond-Langer avoided associations with medical staff *because* of the associations to authority (1978).

Christensen (2004) suggested that the researcher must ask a variety of questions: of themselves, children involved, and with the aim of placing heavy emphasis on power relations. The researcher must glean perspective from the child's perspective as well as understand 'who constitutes the 'adult' in the relationship' (2004). Christensen's formulation of power relations was too simplistic given the BCH research context. Children contested the multiple power hierarchies in the Ward, in the school and oftentimes with nurses and doctors in the hospital. Discipline blatantly demonstrated power through corporeal means. I did not discipline children because it felt inappropriate and unethical. Nursing staff often criticised me for being too 'soft', or 'letting the children walk all over me'. Despite initial misgivings, discipline and its forms became a central focus for the research. Understanding the different ways employees, volunteers, and teachers chose to discipline children highlighted the strain of working and living in an inpatient facility and a general code of ethical behaviour.

Throughout the first two months of research, I was referred to as the 'new doctor', despite constant correction. As the research routine became more familiar, this ceased to be a dilemma, but remained an ongoing conversation with newly admitted children and their parents. Oftentimes new children asked, 'So when is your discharge date?' implying that I was a patient. In addition, the numbers of children admitted to the hospital vacillated in accordance with individual bodily response to treatment, severity of TB, additional medical complications, and family issues. These ever-present shifts radically changed the way I conceptualised time at BCH as well as consistency in explanation of my research.

Although I consistently identified as a student researcher, parents and nurses often misconstrued my explanation. A common question was: ‘So what do you actually *do*?’ Oftentimes children interjected, for example: ‘She plays with us Mummy and is doing a “search”. ‘Search’ was a short hand explanation for ‘research’. I explained the concept of research to parents, nurses, teachers and children as ‘wanting to tell your child’s story to others’. This was followed by an explanation of concepts like voluntary participation, free and informed consent, anonymity and the right to privacy. I never encountered challenges in gaining consent from children or their parents, but often the information provided was conditional, as I will explain later in this work.

Ethics of the Everyday

Understandably, much consideration is paid to situations which may potentially arise in research involving young children or human participants, resulting in ethical misconduct, harm to participants or to researchers themselves. However, the underlying issue at stake is how one manages an ethical issue at *the very moment* it occurs, the follow up and the aftermath for all involved. For every research endeavour there are different considerations to take and approaches which are prioritised over others given the severity of the situation.

As Michael Lambek argued, attention to the ethical ‘provokes reconsideration of the basic terms of the anthropological tool kit’ (2010:7). It is vital to acknowledge that there does not exist *one* ethical ‘blueprint’ within the research experience. Ethics and an understanding of ethical obligations to those we work alongside, and to ourselves as researchers, are situationally specific. As Lambek points out, ‘ordinary ethics’ signals a variety of manifestations in everyday life (2010). As I discovered in my research, ethics are not necessarily concrete, but based on agreements and exercised *in practice* (Lambek 2010).

In this sense, ethics and the manner in which an individual conducts research is highly variable. I agree with Cerwonka and Malkki (2007) that research (with children) is highly improvisational in the first place; but it is the constant reflection on ethics which shape the methodologies employed, an individual’s positionality and the play between those entities. The interplay between fieldwork, theory and ethical understanding are completely entangled. ‘Ethics’ and ethical behaviour are embodied and transcend specific ways of interaction during research; ethics is, essentially, a way of being-in-the-world not limited to research. Ethics is

just as much about *doing* what is right in a specific scenario as it is about maintaining a consistent approach throughout research.

Doing Ethics

In this research, ethics was divided into what I call ‘formal’ and ‘informal’ ethics. Formal ethics consisted of negotiating an ethical ‘paper trail’: the processes facilitated and overseen by governing bodies which focused on ethical conduct and expectations in research. Replete with explicit deadlines, memorandums of understanding, and access through gatekeepers, the process was highly codified. While the name may imply a more casual approach, informal ethics were far more significant in the research process. Informal ethics encapsulated the *doing* aspect of ethical behaviour. These constituted the absolute core of embodied ethics, yet are not stressed enough, because their presence was highly contingent on circumstances and how a researcher chooses to deal with the scenario presented to them. Informal ethics is the *doing* of ethics; it hinges on being an ethical person, not *just* a researcher. Whereas ethical philosophy offers a framework with which to situate certain schools of thought, theory ultimately falls short in the *doing* aspect. This is the most important aspect when confronted with a dilemma in the field. Again, as Cerwonka and Malkki’s work (2007) confirms, bridging the gap between theory and applicability in context is absolutely necessary.

Formalised Ethics

Power differentials and relationships of power are also evident in ethics committees, parental involvement in research, teachers, nurses, doctors and other hospital staff (Grover 2004). The Medical Research Ethics Committee (MREC), in cooperation with the South African Department of Health and the department of Social Anthropology at the University of Cape Town, provided the formalised ethical clearance for my research. The paperwork, the subsequent presentation and approval were expedited processes. This process constituted my formalised ethical clearance. The superintendent and head paediatrician granted permission to the hospital, Ward B, and Ward 3 to conduct research. Many researchers move away from more traditional research methods and techniques in an effort to reconcile these challenges (Young and Barret 2001, Aldridge 2012), something discussed in the last portion of this chapter.

Doing Ethics and Informed Consent

Initially, I employed a formalised consent process mirroring Snodgrass's approach (2010). She obtained consent through individual hand cut-outs which children affixed to an activity board (Snodgrass 2010). The activity board listed the activities for the day and the children provided consent by placing their individual cut-out underneath the activity title. Originally, I thought this method would be more efficacious based on the presentation of consent to each individual participant; it seemed there was no built-in pressure, the process 'looked' fun and it catered to individual interests. As practical as it appeared, the hand cut-out approach to obtain consent was completely ineffectual (see Figure 7). The Ward 3 kids lost their cut outs, forgot the purpose of the white activity board, and generally didn't see a need to 'sign up' via placement of a hand cut-out. One girl, Marissa, age 14 told me, 'I just think, you know, it doesn't make sense.' 'Why?' I asked. 'Well, if we don't want to do something, mos, I would tell you...like if we wanna play, we'll play'. 14 year old Nkosi explained, 'we all know what we like, and what we don't like. The little children – they'll draw maybe. Maybe us big ones won't. No stress sisi'. Many of the younger children voiced concern that the cut-out hands would be taken away by nurses, or stolen by other children. Thus, the hands remained locked away or were taken home on visiting weekends.



Figure 7: Making hand cut-outs, Ward 3 (photo altered to maintain anonymity)

Based on similar reactions, the consent process was on-going; however it was no longer instilled in the hand cut-out exercise. The children preferred to hang on to them, stowing them in lockers as keep sakes rather than putting them under the activity board. I simply asked who wanted to participate in an activity and the children would volunteer accordingly. There was no guess work involved. I found similar reactions when I presented consent forms to parents and their children. One parent explained to me, 'I don't think this is necessary. It's fine. I trust you with my baby. You can ask her whatever.' Another parent mistook the form for a clinical trial consent form. 'Nee man (*No Man*)! Gaan (*Go*)! I don't want this. Don't be silly, mos. Are you making tests on my miesie (girl)?' I explained the research did not involve medical research and she replied, 'No, that's fine, my dear. *Maak so*²⁸.'

A key challenge was trying to make contact and become acquainted with children's parents or caregivers. Children were allowed to go home to visit family every other weekend if their social circumstances were considered 'stable'. I became acquainted with some parents through visits on the weekends, or during 'pick up time' on Friday afternoons. In this way, the consent process mirrored observations by Bray and Gooskens (2006). They framed consent as an emergent process, whereby a partnership forms between researcher and participants; one in which consent is secured over time, through continual reinforcement and engagement. The consent process was negotiated mutually between myself, child and adult participants through extensive explanation of activities involved; but again, this process was not distilled in paperwork or consent forms (Ennew 1994, Boyden & Ennew 1997). I was surprised that some of the caregivers showed little interest, if any, in the research or with what their children were doing. There were other caregivers that seemed intimidated due to their lack of English-speaking proficiency, in which case children intervened and acted as translators. Often children would tell me how 'good mummy spoke' in advance. Lastly, there were caregivers or parents who were completely absent in their children's lives and during the research. This was, for many reasons, one of the biggest challenges. Absentee fathers, an already burdened extended family and deceased mothers leave a legacy of children without anyone to care for them but the state. Often, children are too young to comprehend the magnitude of orphanhood or abandonment.

²⁸ Afrikaans: 'make so'

Boyden and Ennew (1996) suggested that children of different developmental stages and ages are able to participate and understand their participation in different ways. Their thoughts resonated with my work because there were not ways to *exclusively* work with a specific group of children. All 20 children had to be occupied with an activity simultaneously or there were feelings of exclusion. Again, this did not imply for my research that different ethical guidelines were required for working with children as Christiansen observed (2004), but at the risk of not wanting to exclude participants, I provided an array of activities and approaches. I return to this later in my methods section.

Lastly, I consistently provided a clear explanation of how children's contributions may or may *not* be used in subsequent publications. Although I had access to individual patient's files, I decided to exclude this information. Instead I relied on working with children to elicit their stories as they told them to me. The data precludes any individual, visual medical data (i.e. x-rays) because the use thereof potentially dissolves the anonymity of the participants. Pseudonyms are used for all participants, many of which children and adults chose individually.

Violence and Slow Violence: Keeping a 'shared secret'

There were a few incidents where the safety of the child was jeopardised. I expand on this later in my work; however, it is worthy of mention here as the mediation efforts were similar in process. If a child's safety was jeopardised, children most often approached the school teachers or myself. This was true for violence experienced in the home between a mother and father, physical abuse experienced by children emanating from family or caregivers, as well as corporal punishment experienced at former schools before admittance to BCH. There were also two situations in which children experienced physical abuse from BCH nursing staff. Personally, these acts were unthinkable, and yet, because children approached me as a group, they developed conditions with which to negotiate the circumstances. Children were scared of telling nursing staff because they were afraid of repercussions. 'Maybe they think we deserve to be beaten because we are naughty' was a legitimate concern raised. The negotiation process took the form of a 'shared secret'. I agreed (and urged them) to speak Dr. Early as a group, but only as a group. This process demonstrated their awareness of a rights-based framework for both children and patients and the trust they felt towards *some* adults. The teachers and Dr. Early echoed these sentiments in their discussions of maleficence towards children.

The more meticulous negotiations were circumstances revolving around what I call residual violence. Residual violence was the accumulation of negative circumstances which over which children had little or no control. Similar to Farmer's notion of structural violence (1996), residual violence manifested itself on an individual basis and was unique to the child's circumstances and those within their immediate social group. The defining factor was that there may not have been any physical violence present, but the impact on the individual child from these situations was emotionally and mentally abusive. Residual violence manifested through substance abuse, a parent in denial of their HIV status and that of their children, constant unemployment, a parent in jail, the death of a parent, or a custody battle. Residual violence was an umbrella term for all, or some, or one of these things.

Aforementioned situations were common with Ward 3 children. It was difficult not to feel compelled to get involved in some way to ensure circumstances were better at home for many of the children. I did not know how to negotiate these delicate, but destructive life experiences. I felt an obligation to speak to the children about their thoughts and feelings and to find the most effective channel of resolution. The communication was linear; either a teacher or I raised the issue with Dr. Early who would in turn direct the information to one of the three social workers at BCH. Children did not exclude nurses from the 'chain of communication' entirely; on the contrary they were a vital component. Nurses were instrumental in assessing children's circumstances when relatives, parents or caregivers came to visit. In the most extreme of circumstances, parents who nurses considered unfit to care for their children no longer had access to the child support grant and the TB care grant. The child was placed within a house of safety in the Cape Town metropolitan area. Interestingly enough, placement in a 'home' bears the imprint of racial classification of the Apartheid Government, as do many aspects of life in South Africa. Coloured children were sent to a home in Elsie's River, and black children placed in Khayelitsha. If a foster family was not located, a child continued to live in facilities elsewhere in the greater Cape Town area.

The 'little virusy'

Throughout research in Ward 3, roughly a third of the child patients were co-infected with TB and HIV. HIV status was not discussed openly in front of children to prevent stigmatisation and 'othering'. According to the nurses and doctors, the risk of stigmatisation was too great, and it was senseless to jeopardise one's right to sensitive disclosure later in life. I take this cue into the written word here and do not identify those with whom I worked who were HIV

positive. This does not mean that older children were unaware of HIV, other's status or their own. On the contrary, most of the older children were keenly aware of HIV and its implications. When Dr. Early explained how the hospital negotiated the complexity of disclosure and HIV to children, she explained to me 'the little virusy'.

The little virusy was a way to make sense of, and 'read', HIV within a child's body. It became the metaphor for something the child was not responsible for contracting; rather, the child was responsible for making the little virusy happy. In contrast to negative media portrayal of HIV/AIDS, the little virusy was a lifetime friend that will 'always be with you', and a child was encouraged to keep it content. Adherence to ARVs was one way to do this. In essence, the child was not criminalised for something they were unable to prevent and they developed a positive relationship with their ARVs and their HIV virus. There was a concern that some children were not administered their treatment when they would go home for a visit. If a child did not receive their medication while they were in the ward, there was a surveillance system in place: the child consumed their treatment by any means necessary.

Careful and considerate fieldwork is sculpted by ethical considerations – formal, and informal, tacit and unexpected – in the research encounter. The second half of the chapter discusses the methodologies built into the research. Rather than edit out the challenges in implementation of different methodologies, I included all of the methods I tried to employ. If a specific method was more (or less) productive than another, I asked for feedback from children involved in that particular activity. This is one of the ways in which I calibrated methodological approaches. Brooklyn children helped guide me. I hesitate to use the terminology 'child-led', because the process was a mutual collaboration. My child participants were vocal about the methods they perceived as the most useful for research. Equally, they explained methods and activities they felt were 'boring', 'for (younger) kids', or 'lekker' (fun). Further contributions can be made to methodologies utilised in research with children because they have a role in identifying 'what works'.

Putting Pencil to Paper

It is not surprising that drawing is advocated as a research methodology when working with children (Clay et al. 2003, Pridmore and Bendelow 1995, Punch 2002). Drawing differs from a standard interview context where a child may feel pressured from an adult interviewer, embarrassed or shy to respond, or additionally feel they must respond with a 'right' answer.

Drawing enables a research participant to express the ambiguous, the abstract, concepts difficult to convey that often escape verbal articulation. As Punch noted (2002), drawing also provides children with ample time to consider a question or a theme, rather than an immediate response within a verbal format. In Backett-Milburn and McKie's work (1999), adults shied away from certain activities considered 'too child-like', whereas children were enthusiastic to participate. I experienced this in my MA research, when I asked adults to draw 'how they saw TB' (Abney 2011). None of the adults participated in the exercise for this very reason. Pridmore and Bendelow (1995) and Pridmore and Lansdown (1997) write that drawing methodologies are decidedly 'bottom-up' and must take into account the cultural context of each individual child upon analysis.

Most of the children at BCH liked to draw, but this too varied on the day. Thematic questions around home, family and friends, in addition to themes linked to their lives at BCH, framed the process. Drawing was particularly productive, but sometimes there were issues with how children perceived the quality of their work, leading them to destroy data I thought was valuable but they thought was 'rubbish'.

Methodologies: Children as Ethnographers

The 'Children on the Wing' project (Das and Reynolds 2003) inspired the initial methodological outlook. I wanted to enable children to explain to me life as they experienced it in BCH. This desire was accompanied by a number of challenges to implementing activities by myself, on my own. The ages of children in the ward varied from 5 years old to 15 years old. The levels of comprehension differed on an individual basis, and there was always a desire for collective participation at the initiation of an activity. The number of patients in Ward 3 varied from month to month given the amount of time it took for a child to stabilise, cease being infectious, and any arduous social circumstances at home. The standard recovery and treatment time for a child with normal pulmonary TB was six months, but if there were additional treatment complications or extenuating circumstances, that period of time lengthened or shortened. DR-TB takes longer to treat, and thus the stay of hospitalisation was extensive. For example: in the first two months of fieldwork there were two teenagers who were living at BCH for three years because circumstances at home were debilitating, and their level of disease was severe. The *eventual* discharge date every child looked forward to was not necessarily the *actual* date of discharge in all cases. Some children were patients longer

because of above-mentioned scenarios, whilst other children were discharged earlier if they were taking their pills, family conditions were good and their bodies positively responded to treatment.

The other factor which cannot be underestimated was that, despite their appearance, the children in Ward 3 were really sick kids. Although energy levels were generally quite high, rest time was necessary and encouraged. The various drugs ingested by the children were also extremely difficult for them to adjust to and often there were issues with children refusing to take certain pills because of the side effects. Those who were also taking Highly Active Antiretroviral Therapy (HAART) had a 'double dose' or an added pill burden. Some of the child patients were taking a handful of tablets twice daily. The side effects were extreme, and sometimes debilitating. The effects of TB too had major implications for some patients. Mena, at the age of five, was unable to walk for some time because her TB-M had almost paralysed her. Other patients with spinal TB had to be extremely careful when walking, and picking up younger patients was only done with the utmost care. Nurses and child patients explained that violent outbursts from TB-M patients were due, in part, to their medication and their condition. Nurse Jones would point to her head with a tapping gesture and tell me, 'It's the TB-M, Kate. Makes them act crazy at times'. Lastly, children returning from a weekend away would be spoiled by carers with 'luxuries'. Luxuries were deep-fried foods, sweets, crisps and a lot of meat. Luxuries reacted poorly with TB medication, only exacerbated by *not* taking the TB medication or HAART during the home visit. Home visits often had a negative impact on the children, and consequently, the research. Children could not physically participate because they were too nauseous from foods they ate at home, or from failure to take medicines during the weekend. Chapter three elaborates on these themes.

Lastly, there was constant reinforcement from the nurses to not be 'too touchy-feely' with the children. Hugging and kissing on the cheek was discouraged because of contagion, although the likelihood of contracting TB from a child was miniscule and no one wore a mask in the paediatric wards. Strict hygienic rules were in place within all wards. As evident as these rules were, I did not subscribe to them. I continued to treat the children as I would those who were fully-functional and healthy. I saw no reason to do otherwise given the circumstances, and after having witnessed stigmatising behaviours on the behalf of volunteers and nurses, chose to maintain that position. That said, I was never more ill in one year than from November 2011

to November 2012. I constantly picked up minor colds from the children in Ward B and if I thought it was something contagious, I did not come to the hospital. Given that their immune systems were very weak, this was a necessity to protect their often delicate health.

The following methods section makes no mention of interviews with children. I facilitated interviews with adults, many of which were recorded, and many were not. Experiences with children were punctuated by a host of other activities and brief ‘conversations’. Some children were very sceptical of the audio recorder, and some embraced it, recording themselves singing, rambling and otherwise. I felt that a traditional interview format was inappropriate for younger children. I was concerned that the dynamics of the conversation would change if I recorded our conversations. I worried that children would be unintentionally positioned as subservient. Anthropologists who have worked in clinical spaces remark that ‘participant observation is an oxymoron’ and this resounded throughout research (van der Geest and Finkler 2004:1998). Ultimately, the anthropologist either participates or observes. In regards to the children, I almost always felt like an active participant. The children were extremely tactile and affectionate thus reinforcing action as opposed to observation.

Visual Interactive Methodologies: A Child’s Eye View

There is no shortage of literature on child-centred research methodologies. Originally, I developed a series of modules to be implemented over the course of the year. Initially, anything that was deemed ‘interactive’, ‘child-led’ or ‘child-centred’ appealed to research aspirations. Yet, after one month in Ward 3, I soon realised the fissure between theory and practice.

Paediatric hospitalisation in any environment interrupts the previous day-to-day routines of children; therefore some of my methods were not taken up as readily by research participants or, in some cases, at all. I start with the least productive methods and work progressively towards the methods which worked for different groups of children at different times throughout the year. During my research there were two distinct patient groups. The first patient group slotted into the first six months of research from November 2011 to June 2012. The second group were patients from June 2012 to the end of November 2012. The first patient group consisted of many older children, and they were very challenging to work with. There were behavioural problems and there were few who were interested in the research process.

This apathy created conditions which were at times aporetic in scope. This period of time was characterised by constant fighting, both physical and verbal, in addition to very little buy in for research. Methods utilised with group one are discussed in the following passage.

Group one: Journals

I thought journaling or keeping personal diaries was appropriate for this age group. Personal diaries (Zimmerman & Weider 1977), however, require reflection and, as with any participatory exercise, a desire to participate. I provided small journals and encouraged them to write down thoughts, feelings and emotions they felt were relevant about their day. Ultimately, I had no participants. I tried to allocate time for journaling, and attempted to make it feel less like a school activity and more like a fun personal reflection, an outlet. I also had a journal and explained through doing. The feedback was scathing. Whereas they were willing to accept the journals from me, they refused to write. They simply didn't want to write. They wanted to watch television or asked me to hire out movies. At the end of my first week, one participant out of 18 had completed a few pages in her journal and was promptly discharged two days later.

I had also envisioned using written life histories during the journaling time, or at least hoped that perhaps I could initiate a process where participants would feel comfortable enough to write down their feelings about being hospitalised. Bertaux (1981) advocated for autobiographies or *written life histories*, where participants were left with their own thoughts, writing implements and paper. The idea was to minimise the researcher's presence (hypothetically), thus minimizing the researcher's influence. This process ideally creates what Green and Hartman (1992) refer to as an 'inner dialogue' (cf Torstenson-Ed 2007:49). The life history method was used by Torstenson-Ed (1994, 2007) in addition to the 'round-tour' approach. The round-tour approach uses a specific context to jog memories of those participating. Simultaneously, the researcher audio records the recollected memories from the respondents. I also attempted this technique in a bid for a more 'active', group-oriented activity and to alleviate what I perceived as potential pressure. Again, group one was uninterested.

I approached the teachers for their thoughts. 'Do something less school-like', 'just play with them' and 'whatever you do, just make it fun'. Theresa insisted that by the time they were done at school, they were too exhausted to do anything scholastic.

Picture work

Dell-Clark (2003) used the Metaphor Sort Technique (MST) to elicit verbal response to visual stimulus. Dell-Clark presented pictures which the participant associated with negative or positive attributes in relation to their illness (2003). I attempted this method with group one and a fist fight broke out in the ward. Unfortunately, fights were common, and in the context of this activity led me to stop initiating this method.

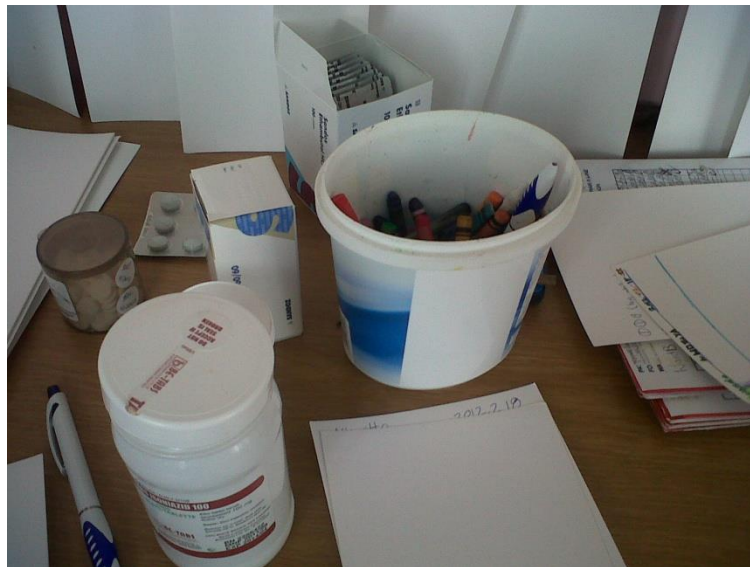


Figure 8: Pill charts, Ward 3

Pill Charts

Figure 8 is a photograph taken by one of the children in Ward 3, Rosa. This was at the commencement of the pill chart activity. This activity was born out of the necessity to ensure that each child knew their treatment regime by heart. After a conversation with an eight year old patient, it was made obvious that she knew her medicine, but not the full pharmaceutical names. This situation is explained in more detail in Chapter Three. In the following Figure 9, my personal pill chart.

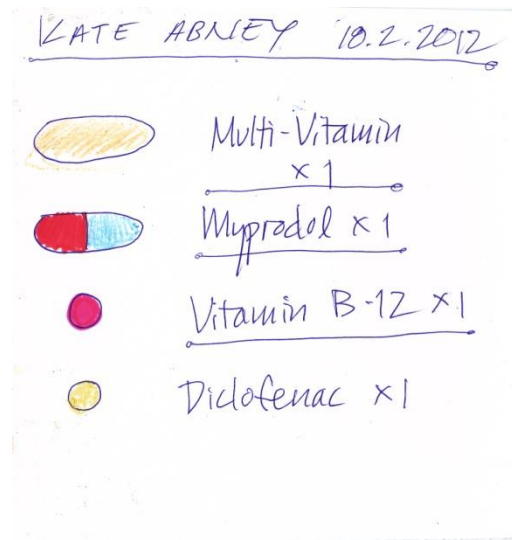


Figure 9: Kate's pill chart, Ward 3

Maps and Mapping: Body Maps

Young and Barrett's (2001) work with urban street children in Uganda emphasised creative participatory methodologies.²⁹ Young and Barrett (2001) recommend four different methods: 1) mental maps; 2) thematic and non-thematic drawings; 3) daily time lines; and 4) photo diaries (2001:143). Gooskens (2006) asked participants to create maps of their neighbourhoods, identifying the 'safe' or 'dangerous' areas. I utilised this approach with much success in my MA work (Abney 2011). I thought that by creating 'spider map' drawings, it may help illustrate the ways children conceptualised transmission and space. Again, the children in group one were uninterested. Group two developed some maps of BCH which I feature in the next chapter. The body-mapping exercises I tried with group one were not taken up because they were 'boring'. I did not use this method on a large scale with group two because it was too abstract, one of my oldest children said he didn't understand the objective of making the body map.

Of Time Lines and Camera Work

In Young and Barrett's research, children developed symbols which represented certain activities and temporal sequences (2001:146). I originally thought that timelines could be

²⁹ Also see West (1999), Woodgate (2001), Morgan et al (2002)

formatted to explain the child's conception of transmission, the chronology of their own TB infection and treatment. I wanted to link the timelines with miniature photo diaries with the provision of disposable cameras. The disposal camera project involved patient group one, but only the children who were consistently engaged in my research. Eight older children (aged eight years old to 15 years old) were selected based on interest. I instructed them to take the cameras home and take pictures of their weekends. I encouraged them to try to take pictures of things that were important to them: their home, favourite food, play areas etc. I tried to explain to avoid taking too many pictures with people's faces.

Out of the eight children, one lost their camera, three cameras were stolen on home visits, and the other four produced photographs which were of family and friends or within BCH. While the photos were meaningful to the participants, they could not be used in the research because I had no way of making them anonymous and thus the photos were unusable in my final thesis from the subjects captured.

The timeline aspect was another activity which did not work in practice. BCH children preferred an interview format: discussing the 'before' and 'after' BCH. The paper and materials provided for the timelines were only utilised during the first timeline workshop, after which all children's timelines disappeared (like so many projects we worked on). Others did not understand the concept at all, and decided to draw instead.

Mood Boards

Another project which worked really well with group one were mood boards. A mood board was a large piece of butcher paper hung from a door or a blank area on a wall. Each board had a different title and the space below the title was blank. Children were encouraged to write or draw below the title. Some of the various titles read:

'Today I feel...'

'Things that make me happy'

'Things that make me sad'

'I am angry when...'

The mood boards hung in the ward for a week. Afterwards, we sat as a group and discussed the contents, and sometimes acted out different scenarios. Acting out scenarios provided a non-judgemental space to mediate issues amongst some children in patient group one.

Unfortunately, the mood boards also disappeared from the ward. None of the children or staff could tell me what happened to them. Children thought the boards were helpful.

Marissa explained, ‘Well no one can see that you’re writing on it you know? I can sneak away and write and tell someone without going to them.’

Zwai explained, ‘I think they’re ok. The little ones don’t know what to do – but we do...’

Nkosi: ‘It’s cool sisi. I like it because I can say how I feel’.

Children’s Radio Workshop

The Children’s Radio Project (CRF) facilitated one workshop per week over the course of three months with group one. CRF worked with big organisations like Partners in Health in an attempt to share stories of paediatric illness worldwide amongst other, pressing social issues.³⁰ One key challenge was potential TB transmission. We were very conscious about how to train and teach children to use the microphones without spitting on to them or holding them too close to their mouths. Whereas the children were excited to interview each other, as well as nurses and doctors, one workshop for one hour and a half per week was insufficient to produce a substantial amount of data. There were a few topics and themes the children identified as pertinent to discuss. One such workshop revolved on medicine and its side effects. Whereas this was a productive workshop, the data produced was not distinct from my day-to-day conversations with children without the participation of the CRF. Given the behavioural issues we experienced with group one, three months of these workshops was inadequate. CRF expressed interest in continuing their work with children at BCH, but continued their work with young adults who were no longer minors with more success.

Before BCH

The following section draws on portions of conversations to introduce Ward 3 Children. I start with miniature biographies from patient group one and move gradually to patient group two. These conversations are a bricolage: through informal group discussions, some patient review sessions, radio workshops and one-on-one dialogue. All children recognised that there was a ‘before’ part of their lives, a preface to their admittance to BCH. Most of the children spoke to their onset of TB with extreme candour and an acknowledgement of *who was responsible for*

³⁰ See the CRF website for more info <http://www.childrensradiofoundation.org/>

infecting them. Children were encouraged to speak to what they felt comfortable with in addition to what they valued the most in their explanation. I explained that I wanted to know their stories, but they only should tell me what they felt comfortable with. In many cases, children only told me when they felt comfortable, which meant that I was constantly prepared to engage if they felt like participating or participating through ‘non-traditional participatory means’.

Nkosi: ‘My chest was not feeling right’

Nkosi was fifteen and lived on the outskirts of Khayelitsha. He started to trust after he had been a patient at BCH for a month and a half. This marked the end of his infectiousness period, where he could safely remove his face mask.

‘I’m staying there in Khayelitsha, it’s nice to stay there because we’re playing soccer...maybe when we grow up we’ll be on TV. Every weekend we’d take a tournament in soccer.’

‘My father works in Athlone by a car place. I also have an older brother who is 23 years old. I have an older sister too. She’s 19 years old. I also have a sixteen year old sister. They both stay with me too. My brother and I stayed at home and shared a room. I think because we slept in one room I got the MDR from him. He took his pills. My mother did give them to him and he took them. I know because I watched. He finished his treatment and went back to the Eastern Cape.’

‘I was so tired. I could play soccer small (a bit). My chest was not feeling right. I was playing for only a few minutes. I told my mother I’m not feeling well. They took me to the clinic. We did find it in the x-ray. I ate 6 months of treatment. The sputum was right, but the x ray showed TB still. We listened to this radio show every week. It comes on the air from Khayelitsha...every Thursday there is a show and my mum called in to speak to the sister on the radio. The sister said she could help us. Then Prof said to come to Town 2 clinic and we did come. That was 6.12.2012. They looked at the x-ray and they changed their minds. “Come to Brooklyn Chest” they said to me. “It’s nice there. There’s a school.” I was scared small (a bit).’

Gabi

One afternoon I sat with Gabi, a 9 year old from an area called Capricorn. That day, she was allowed to go back to school, and I stayed behind in Ward 3 with her to tuck her in before her nap. She took the recorder from my hands and sat on her bed, matter-of-factly explaining how she arrived at BCH:

‘This is my third time with TB nuh? 2009 was the first time I had normal³¹ TB with my sister. She was five. My mum just cried and cried. I was with my gran and grandpa and mum and daddy. Gran died. My mummy left my dad you see, and I followed her. 2010 was the second time and it was me and my sister again, except she was then six. The third time it’s this MDR. And it was December 2012. When I came here, all the children were gone. I came here and Rosa was still here. The two of us. And then Khadija saw me. I came over the weekend and then for the Christmas weekend I got to go home. My chest was so sore. I couldn’t breathe proper. I was tired and sleeping all of the time, every day. I could do nothing.’

‘My sister is now eight. I have TB alone. My brother is three years old. My other sister is 2 and half months old and I have another sister too. There’s six of us in total. From my real mum it’s four kids...then the others. I stay with my mummy and step daddy.’

Marissa

My introduction to Marissa was characterised by her refusal to interact with the rest of the children in patient group one. ‘Just because I’m here doesn’t mean I have to be friends with them Kate’, she told me. At the time of her stay in BCH she was 11 years old, but she was exceptionally tall for her age, so many people thought she was older. She eventually warmed up to the other children, but before this occurred she would become possessive over me, our time together and demanded much attention. She explained how she had terrible headaches and how bright lights and sounds would make her ‘deer mekaar’³². We primarily interacted through informal conversations because Marissa refused to participate in group activities, and was very wary of the audio recorder. She opted for cell phone texting and phone calls when I was not physically present at BCH.

Whereas I became close to many of the children’s families and caretakers during the research period, Marissa’s family was an exception. I visited them in the informal settlement of Blikkie’s Dorp where they had been staying for two years. Her mother explained to me, ‘They don’t know what’s wrong with her Kate. They’re keeping her on the MDR drugs to be sure’. Before coming to Brooklyn, Marissa attended her local clinic, Tygerburg Hospital, eventually to be admitted to BCH. Like many of the paediatric patients, she met other children who were later admitted to BCH while negotiating the governmental health care system in Cape Town.

³¹ Pulmonary TB

³² Afrikaans vernacular, multi-meaning: crazy, confused, dis-organised, naughty

Rosa

Rosa came from a small farming community about 3 hours outside of Cape Town called Porterville. This was her second stay at BCH and she had developed MDR-TB because she stopped taking her tablets on a regular basis. During research she was soon to be thirteen years old. I tried to discuss her personal patient history, and Rosa refused to discuss it with me. There were potentially many reasons for this. I eventually learned that she had defaulted on her treatment multiple times and my questions may have made her feel uncomfortable. However, she was always adamant in participating in the 'doing' of different activities, just less interested in talking on-on one. She readily commanded attention in organising the other children and was always very helpful in facilitating other activities whether she participated or not. She was also very vocal in explaining to me what she deemed 'important enough' for my research.

Sierra: 'The TB sticks to me still'

'In 2009 I first got TB. It was normal TB. I was at a private hospital. They gave me six months treatment and I drank it full. I was just lying there in my bed. I was sleeping in my clothes. My clothes were all wet. My mummy took me to the hospital. Every time they took my temperature it was 40 degrees Celsius. In 2012 now, I have resistant TB, They stopped my treatment because of this (points to her neck). This neck is swollen. It's in my glands...glandular TB nuh? The first of January, my family was at the beach. I felt very poor nuh? My family took me to Keitzerville Medical Centre. I liked it there, they had TV. But it was big.'

K: 'What was big? The hospital?'

S: 'No mos', my neck – it just swelled up like this (makes gesture with her hands).'

K: 'Oh ok, I understand now.'

S: 'They said they were going to operate. They took the pus (pus swab of the gland) and did the sputum test. It showed I had TB. I took the tablets and they weren't helping. I had another operation.'

K: 'What kind of operation Sierra?'

S: 'The kind that hurts. The kind where they dig thing out, and cut, and peel, and scrape the dingus (the TB) away. That kind. It's *meant* to help, but it *doesn't*. The TB sticks to me still. So the TB stayed. I took more tablets and then an operation and they said it was MDR-TB. They gave me tablets, it swelled up again. They took out the stitch, and the pus came out. I went to Tygerburg, and Prof. saw me. He said I must come this side. March 14th 2012 that was the date I was in Ward B. Just little ones (children) there. So boring Kate. I have friends now here. Also, I'm asthmatic...if I run too much I can't breathe. I cough and cough and cough. But then Gabi will help me with my puffer. I'm also Muslim...did you know that?'

Carlito

Carlito was my ‘longest stay’ patient. He was admitted mid-January 2012 and only left a month before I completed research in November of 2012. The first month at BCH, Carlito was very quiet. Although he was eight years old, he was stunted in stature and there were rumours that his mother was a tik user and alcoholic. According to the social worker, Carlito’s mother was a foster child, but she had a sister who ‘sort of looked out for her’. Her boyfriend was much older than she, somewhere in his sixties, whereas she was 35 years old. He was allegedly very abusive to her, which raised concern about his treatment of Carlito. She had been living with him for some time, and his pension helped sustain the household. It was unknown if he had a job, but Carlito’s mother did not.

It would be three months before anyone came to visit Carlito. Unlike other children, he didn’t struggle to take his tablets. Carlito was from Belhar, a predominantly coloured area which makes up part of the Cape Flats, Mitchell’s Plain area of Cape Town. Carlito constantly imitated the gangsters he saw in his neighbourhood. Pantomiming a gun with his hands and speaking the *taal*³³. I include some thoughts from field notes below:

‘The one thing that really stood out for me in relation to Carlito’s appearance is that he looks like a FAS child (foetal alcohol syndrome)... he has very big eyes and his head is also big in relation to his body. He’s just so small. He also (and still has) a lot of teeth growing in on top of baby teeth which are literally rotting out of his mouth one by one. The doctors tell me that his adult teeth will straighten out, but the dental hygiene was non-existent before coming to BCH and probably indicates the type of food his mother can afford.

Carlito explained to me that his father was killed in an altercation in Belhar. He said ‘he got hit on the *kop* (head) like so’, as he gestures with his fist bumping into his head. ‘It was a brick, Kate’. He did not remember how long ago his father died and had no memories of him. The two times Carlito’s mother came to visit I was present, but she was not a regular visitor.

Themba

Themba was admitted to BCH on June 13th 2011, six months previous to my arrival at the hospital. He was nine years old despite his appearance and developmental abilities, which are stunted to a certain extent. He was from the township of Nyanga and was generally considered

³³ Afrikaans: language

a possible MDR-TB case. Themba had been living with his grandmother until she passed away. His mother and father were estranged, and he did not receive regular visitors, and hardly, if ever, was granted weekend leave. His mother was an MDR-TB patient and had psychiatric problems. Apparently she was on the waiting list to be admitted to BCH again as she had previously defaulted on treatment, and thus infected Themba. She was a 'known defaulter' according to Brooklyn staff. Throughout the course of my research she was a patient in Jooste Hospital, also located in Cape Town. Themba never spoke about family, his mother, or relatives.

Ricardo: 'Children don't get told nothing'

'I did play in the sun. I did start getting headaches. Then I got to Hillcrest Hospital...that place is big Kate. My mother did go with me. We went to clinic first though. They gave me two lumbar punctures at the hospital by Paarl. They went pow pow! I did sleep afterwards. So they told me I had TB-M. My mother told me this, not the doctors. The doctors just say to the mothers the things happening nuh? Children don't get told nothing. The doctors said nothing. I couldn't walk...run...I didn't want to eat. I sleep the whole day. My mother must go and fetch the number...but I'll take pills at Hillcrest Hospital. She works now at a shop. My dad passed away...a train did bump him. My brother is 20 and my sister is small...she's seven.'

Ricardo was 11 years old during his second stay at BCH. Contrary to Ricardo's understanding of his father's death, his father passed away in 2006, and infected Ricardo with TB. He lived in the farming community of Wellington. His mother used to be a grape picker on a vineyard and now she works in a factory. She was applying for a disability grant at the time of research and visited him infrequently. He was very stubborn taking his treatment and started becoming more aggressive towards his mother as he becomes a teenager. Ricardo and his mother lived at the back of their granny's house in a wendy house (small trailer home). His mother also became infected with TB and was unemployed and finishing up her treatment.

Scott

Scott arrived at BCH in October of 2012 and came from Paarl. His mother explained to me that he was 'a child of God', and the family were church-goers. Like many of the bigger personalities at BCH, Scott was initially quite shy. At ten years old, he started emerging from his shell and was extremely disruptive, aggressive towards the girl patients and would follow them into the toilets sometimes. His mother had been an alcoholic for a long time and recently 'found God'. She had left Scott in the care of his father and uncle, who were very supportive.

Phelo

Phelo's arrival at BCH in July 2012 marked an extreme shift in the group dynamics of the Patient 2 group. At 9½ years old he was described in a patient review session as being a 'severely clubbed and stunted little boy'.³⁴ In addition to physical or medical characteristics, Phelo was disruptive and sometimes aggressive. His mum was always described as being 'a difficult, stubborn woman'. My minimal interactions with her were met by silence. Nurses would speak about her as 'reckless' and 'uncaring'. Staff speculated that she was in denial of her HIV status and refused to get tested. Theresa and Teacher Grace were concerned that her denial would negatively impact Phelo, and that he would default on his TB medications during weekend visits.

Gift

Gift, who featured at the beginning of my thesis introduction, was one of the older patients who also lived in Ward 3. He had contracted TB in 2009, and was admitted to BCH in late February 2012 for MDR-TB after experiencing treatment interruptions. The following is an excerpt from a Children's Radio Programme session we facilitated with the first group of children I worked with. Children were asked if they wanted to participate in sharing a small story about a difficult time in their life. Here is his story which helps frame some of the challenging circumstances Gift faced during his stay at BCH.

'Hello my name is Gift and I stay in Gugulethu. I was playing with the iron at home and my mother was in the kitchen. I was going to fetch water and she beat me. My father came after and he beat me and then my mother and my father fight and they broke up – both of them. Then my father go to stay in Kimberley and my mother is dead. Now I'm staying with my aunty. This Friday I'm going to weekend. Yes...and I'm going to see my Granny. My Granny is sick'.

³⁴ Clinical terms associated with malnourishment and vitamin deficiency

Group Two: Back to Basics



Figure 10: Dough activities, Ward 3

Working with the second group of patients was a distinctly different experience. There were fewer older children, and the personality conflicts were almost non-existent. They were enthusiastic about almost anything, and generally I had a lot of fun working with them. This group was filled with children who were hungry to draw and create things. They also liked to play outside and did not fight as often as the children in group one.

Dough and Drawings

Given their propensity for drawing and creative exploration, I encouraged them to draw, and paint whenever it was suitable. Exploring metaphors of chronic illness, Weiss used a ‘free association’ approach (1997). Participants were asked questions like ‘How do you see cancer?’ (1997:459). Weiss found that all of the participants preferred to draw their responses. In my MA work (Abney 2012) I used this method and it provided insight into children’s conceptions of TB and conceptualisations about how TB is transmitted. At BCH, with group 2 children, I found they preferred to play with dough. I provided different colours of dough and the children sculpted their different ideas of what TB ‘looked like’ to them (see Figure 10). It simultaneously acted as a ‘wind down’ activity from school, as well as something they considered fun. Another theme emerged from the dough activity, one which was unexpected. Children in group two were far more focused on food and ‘home’ than those in group one. Food became a common conversation topic, especially when we worked with dough, because children sculpted the food they desired.

Onwards, into Ward 3

The following chapter sketches the daily routine within the ward and details how doctors and nurses figured the paediatric patient. This figuration is specific: it relies upon biomedical regimes, rituals, tasks, and routines. The microcosmic world of Ward 3 situated nurses, doctors and child patients within social and biomedical processes undergirded by personal experience and evidenced-based medicine. It was in Ward 3 that the child became a biomedical object, and re-enacted the rituals their bodies were subjected to, and eventually came to embody. These performances illustrated emergent knowledge about TB and its practices, those that performed them and what, if anything, could be expected for the very uncertain future.

Reading Bodies, Seeing Signs: Patient Life at BCH



Figure 11: Ward 3 from the edge of the Visitor's parking lot, front entrance BCH

This chapter focuses on the people who shaped and reinforced the figuration of the *paediatric patient*. It also draws attention to medical and technological processes that enabled a particular *reading* of a child's body in the clinic as a material and investigative interface, which is a trademark of biomedicine.³⁵ Biomedicine is saturated in protocols and products which are visual, however the body is the fundamental starting point for inquiry. Oliver Human provided a useful explanation:

‘A protocol structures, “rationalizes,” and prioritizes certain ways of thinking above others and aims to make thought processes efficient. Efficiency is created by the belief that individuals can belong to particular categories or population groups, and doctors simply need to place individuals into the correct group for a correct diagnosis.’ (Human 2012:225)

Here, the child was *the* object of the Foucauldian (1973) biomedical gaze, mediated through the methods that framed it: sputum samples, smears, x-rays, lumbar punctures, blood tests, gastric washes and a patchwork of medicinal regimes. It was through these protocols that children became patients as much as through the physical relocation and isolation from their homes. Although isolation is arguably the most profound result of this model of TB treatment, children's worlds were made more complex through their compliance with biomedical routine. Their bodies were ‘read’ by physicians and nurses. They were disciplined in pill-taking, and they were expected to embody a mentality of adherence and responsibility towards their

³⁵ See: Gordon (1988), Goode and Delvecchio Good (1993), Howell (1995), Lock & Nguyen (2010), Levine (2012)

medical regimes. With the overwhelming presence of biomedical technology and practitioners who enforced curative strategies, there were few aspects of daily patient life at BCH that were *not* under the watch of an employee, be it a doctor, a nurse, a teacher or a non-medical staff member. Children's bodies were fundamentally *bodies at work*.

How children *came to learn or embody* patienthood forms part of this chapter's enquiry. This process is related to how doctors, nurses and caregivers contributed to the figuration of the child patient. In what ways was the patient-making process legible? What did it mean to children to be an institutionalised paediatric TB patient at BCH? The chapter tracks the admission and arrival at the hospital through the narratives of BCH paediatric patients set against the backdrop of the social, economic and ethical dilemmas faced by those treating them. The perspectives of Ward 3 patients evidenced gradual assimilation to daily routines, medicine regimes and procedures enforced by medical staff.

And yet, simultaneously, the prevalence of MDR-TB in South Africa demonstrates the continued struggle with striking a balance between individual rights versus the collective good of society in regard to treatment models. Enforced isolation from one's community has been met with stories of patients absconding and alleged violations of constitutional rights have emerged in recent years.³⁶ In addition to this, I draw attention to the social, economic and infrastructural processes, which were made visible through individual paediatric cases. Jiao Biehl (2005) has called these processes 'technologies of invisibility'. They warrant consideration because of the interplay between individual experience of disease and materialisation of these processes in a child's life. These technologies were seen through bureaucracy, negligent health care workers, and inconsistent record-keeping and imperfect diagnostic techniques. Technologies of invisibility rendered paediatric TB patients and their care takers as largely absent, discarded 'waste' thrown to the margins, until they arrived under the care of BCH. As Biehl cautioned, people become *absent things* in the very processes which involve them as patients (2005).

It is here that ethnographic research rooted in a critical medical anthropological paradigm is well positioned to take up these *invisible* parts for analysis, to create a *more visible whole*. As Biehl wrote, 'Concrete biological phenomena are intertwined with environmental conditions

³⁶ See Harper (2005), London (2009)

that are part of a grander human life-context, and it is in this complicated web that the individual's illness experience is constituted' (2005:4). As theorised by Farmer (1999, 2003) Biehl's 'technologies of invisibility' can be read as constituent of structural violence and pathologies of power. As an individual child's body was scrutinised for TB symptoms, societal disjuncture too came into view. The following section marks the beginning of the journey to BCH.

'You tell them Brooklyn'

The twelve minute car ride from my home in Observatory to Brooklyn was characterised by scenes of business and busyness. Koeberg Road takes form from the N1 turnoff of Section Street and stretches into the Northern Suburbs. Sitting on a cul-de-sac, BCH is partially hidden from the buzz of a neighbourhood waking up: teeming with used furniture shops on street corners, hurried minibus taxi drivers, horse-drawn cart scrap collectors, and vegetable vendors. A short walk from main road, the hospital sustained an isolated, deceptive sense of solace for me. From the outside looking in, the hospital appeared calm, yet from the inside it was far from peaceful. Both sides of the vast property were cushioned by residential streets lined with low-income housing facilities and single-family homes. A grassy open space and non-descript warehouses stood adjacent to the back side of the property.

A large boom gate and security guard kiosk marked the entrance to Brooklyn. Tall metal fencing enclosed the hospital on all sides. Visitors signed in whether on foot, or by car. The sign-in sheet required the following information: name, purpose of visit, intended area of visit, contact details and registration of vehicle. A grassy lawn separated the kiosk and guest parking area from Ward Three. There were three entrances to the Ward, each equipped with a buzzer and intercom system (see Figures 11, 12, and 13). This system was installed three months into my fieldwork for added security. The photographs in this chapter were taken with my cell phone by paediatric patients, thus forming one methodological component. Most of the children were cell phone savvy, and constantly nagged me to play with my phone. Despite my initial discomfort, I eventually relented because they were careful, but enthusiastic to 'take pictures' of Brooklyn, to 'show what it's like here'.³⁷

³⁷ Rosa, personal correspondence



Figure 12: 'Kitchen side entrance' Ward 3



Figure 13: 'X-ray side entrance', Ward 3

As Shelly, age 9, explained:

'If you don't have a car you can come by train or taxi. You take the taxi and it will drop you there by the gates. You tell them 'Brooklyn'. People know why you are here or why you come here. You just come in by security and sign your name. You'll see Ward 3 and Ward B...Ward B is for the small children and Ward 3 is for our size children...the big kids.'

Lolly, age 5, added, 'Then you press the gate (button). You press the *dingus*³⁸. It goes ding dong.'

³⁸ Afrikaans 'thing'

S: 'Then you say "I'm Shelly or I'm Kate"...and they will let you in. You open these gates when you want to get in, and you close them to keep people out of Brooklyn. It's safe with these gates that lock.'

K: 'Do you have gates and locks like these at your house?'

S: 'No...A small one on the door. It doesn't keep people out. You must be careful that side, *mos*³⁹. There is (sic) many bad things that side.'

L: 'By my house there are stairs and stairs and stairs. And little *hokies*. But this 'hokie 3' is different.'

While most of the children referred to Ward 3 as the 'ward' or 'Waad', Lolly referred to it as a *hokie*, or small, enclosed space. In her neighbourhood of Bonteheuwel, *hokies* served many purposes: *shebeens*⁴⁰, *tuk shops*⁴¹ or the front yards of people's homes demarcated with fencing or old re-used, wooden shipping pallets.

These short conversations characterised the types of exchanges I had with children. A question about BCH elicited a larger discussion of life at 'home', and children drew comparisons between BCH – their 'new' home – and their 'real' home. Some children identified with their 'real' home, refusing to make likenesses to Brooklyn. Similar to Rosemary Blake's (2009) research in a paediatric oncology ward, children maintained a distinction between 'real' and 'temporary'. In Blake's work, children who lost their hair due to chemotherapy treatment explained through photographs what they 'really looked like' (with hair). Similarly, paediatric patients explained how their 'real home' differed from the ward. Additionally, concepts of home emerged in Marshak's work (2013) around adoption in Swaziland and home-making practices.

However, the act of getting to, or arriving at BCH from 'home' was not the same for everyone. Some arrived in buses, taxis or trains. Other children arrived with the complementary transport provided by the hospital. Children knew the costs of transport in addition to transport time. Less clear were children's understandings of *how* they came to live at BCH. How did children perceive their own diagnosis? How did they *come to know* they had TB? My research findings

³⁹ Afrikaans vernacular, similar to a confirmation: 'you know what I mean?'

⁴⁰ Informal drinking establishment, or liquor seller

⁴¹ Also known as a spaza shop; a shop selling anything from sweets to toilet paper and other goods

demonstrate that children were aware but didn't necessarily understand why they were living at BCH.

'Doctors told me nothing Kate. I was put into that taxi (patient bus provided by DoH). That's it, Qha!' -Zwai

'I just knew there was a school here...I thought that was funny. Why would there be a school here at Brooklyn?' -Nkosi

'I ran away when that taxi came. Yoh I run (sic) far away. But my mum did catch me and put me in (to the taxi) to come. From Retreat...that's far!' -Gabi

Rosa explained further, 'You know *mos*'. I already had TB before and I was at Brooklyn before this too. Is it easy? No. Did I listen? No. But- I can check you to see if you're clean.⁴²

'I just didn't want to come. The whole thing was too confusing. I didn't even know where BCH was!' - Marissa

The first time I met Rosa she examined my chest as if I was a patient. She repeated the exams daily for a month. She tapped my chest, checked my pulse and reported back. When I asked what she was doing she responded, 'Obvious! I need to see if you have TB *mos*. We all have TB. Do you have TB too?' My uncertainty prompted her affirmation: 'Hello, that's why I'm checking.' She tapped very hard on my chest with her index finger and middle finger extended with her other hand placed on my chest. She carried on tapping and listening to the hollow drum sound her fingers produced. 'You're clean, no TB. I'll check tomorrow, ok? Just to make sure.' Within the first month, as with the admission of new patients, children were curious if I too was 'like them' and had TB. Other times they asked about my discharge date. Another little girl, Gemma, made her own stethoscope and showed me how to listen for signs of TB in the lungs. This is shown in Figures 14-16.

⁴² TB-free

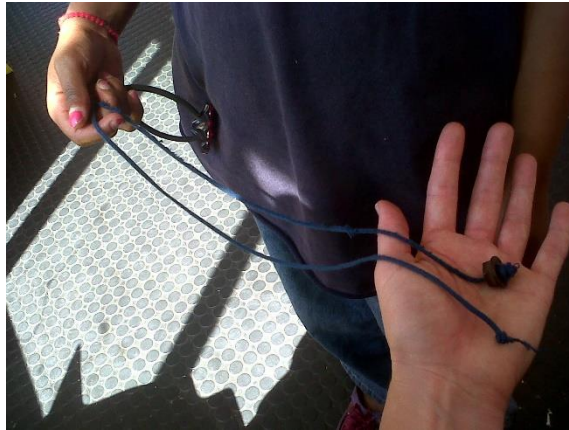


Figure 14: 'I made it to listen.'-Gemma. Gemma's stethoscope, Ward 3



Figure 15: 'I'm listening to hear you breathe, Kate.'-Gemma



Figure 16: 'And then you make so. You see? I can tell if you have TB or not.'-Gemma

The gradual assimilation to patient life was marked with these behaviours and performances, although it varied individually. Children's understandings of their bodies as well as new,

different bodies (like mine) were scrutinised with the same learned set of biomedical protocols. From Rosa's chest-thumping to Gemma's make-shift stethoscope, children actively produced patienthood by participating in these biomedical rituals.

Life 'Inside'

After the 18th century, hospitals shifted focus from welfare care centres for the poor, to include practical medical education in much of North America and Europe (van der Geest and Finkler 2004: 1997). As Foucault observed, hospitals became places of instruction and surveillance, whilst patients became the foci of observation (1973). Erving Goffman's *Asylums* (1961) introduced the idea of the *total institution*. Goffman's definition follows:

‘A Total Institution may be defined as a place of residence and work, where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life’ (ibid:11).

Goffman's ethnographic work focussed on a large mental health facility in Washington, D.C. He showed minimal interest in the medical effectiveness of the facility, but focused on the identity formation and ‘re-education’ of the patient population. It is hardly surprising that Goffman's *Asylums* (1961) and *Stigma* (1963) have had an immense impact on the ways in which sanatoria life have been approached by medical historians. Goffman provided a language with which to identify social, political control over non-normative bodies being treated for TB in sanatoria in North America, the United Kingdom and Europe. TB historians⁴³ have also recognised the political and social control aspects of sanatoria and thus minimised their therapeutic efficacy, yet few of them concerned themselves with a deeper analysis of patient life for TB sufferers within these facilities. Hagiographic accounts lauded the onward march of medical discovery (streptomycin as a cure and other antibiotics) and the pioneer surgeons responsible for cures and new healing strategies (many of which were abysmal failures). Foucault contributed to many of these distanced accounts with his collected works (1973, 1975) which seemed more concerned with the institution and its organisation and much less with what the medical historian Roy Porter called the ‘patient view’ (1985). Flurin Condrau has observed that, ‘It is thus imperative to overcome the notion that the institution

⁴³ See Bryder (1988), Rothman (1992, 1995)

exists independently of its inmates and that patients are mere objects of institutional therapy' (2010:80).

Van der Geest and Finkler (2004) also suggest that hospitals are frequently characterised as monolithic, biomedical entities which are globally uniform in structure and function. Alternatively, they propose that, '...biomedicine, and the hospital as its foremost institution, is a domain where the core values and beliefs of a culture come into view' (2004:1995-6). This position is shared by other theorists, biomedicine is a culture⁴⁴. Schneider's (2001) work in China demonstrates too that there are intricate continuities between life *in* the hospital and life *outside* of it. A number of scholars (Tanassi, Gibson, Zaman 2003 ci Schneider 2001) support the claim that life within a hospital is far from being divorced from 'the real world'. Rather, hospital life is 'shaped by everyday society' (van der Geest and Finkler 2004:1998). Again, the work of Blake (2009) in the Red Cross Children's Hospital and Van Heerden's (2009) ethnographic research in St. Joseph's Home merit a revision to Goffman's *total institution* (1961). Mulemi's (2008) work in a cancer ward in Kenya and Livingston's (2012) in Botswana substantiate the porousness of these types of facilities. At Brooklyn, the merger of the total institution, patient experiences of the sanatorium and the relationships between all actors within the hospital help to sustain and individuate personal experience. Far from being written into ambiguity as medical historians have tended to do (Condrau's criticism), patient experiences and those of their medical caretakers, come to the fore of critical inquiry.

'We look like pilchards in a tin'

Map-making exercises have been shown in other works to be an efficacious way to glean insight into children's spatial understandings. Reynolds (1989), Bray and Gooskens (2006) and Marshak (2013) utilised similar techniques by asking children to shade in or identify places they were 'allowed' to go, 'safe' or 'fun' places, and places that were considered dangerous. One dichotomy shared in these works was the appraisal of a space or place as 'good', 'bad', 'dangerous' or 'safe'. These polarities and labels were not present in my research; rather, children's observations hinged on the events, procedures and people encountered within these

⁴⁴ See Lock and Scheper-Hughes, (1987), Feierman and Janzen (1992), Helman (2001) Lock and Nguyen (2010), Levine (2012), Livingston (2012).

spaces. For instance, the ‘x-ray place’ was where the x-rays were taken, the ‘beep box’ where audiology appointments took place.

In the map-making exercises, group one produced no maps. Group two however, drew their understandings of BCH for me readily, but provided minimal explanations. With these brief spatial mappings one can grasp the general layout of BCH.

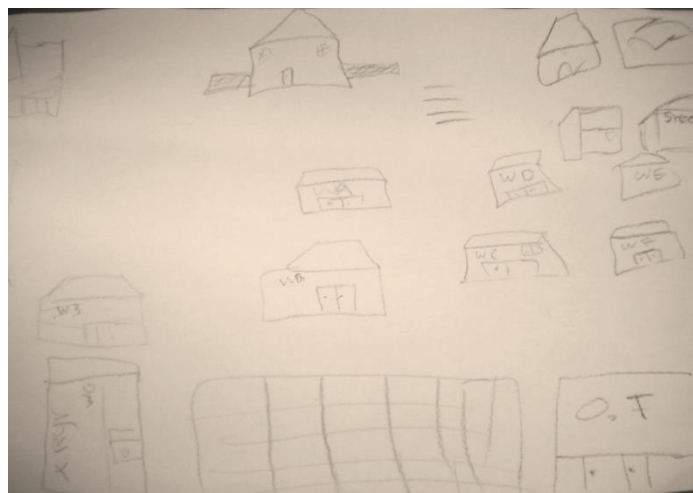


Figure 17: Gladwyn's map of BCH

Gladwyn, age 13 described Figure 17:

‘This is my map. I don’t have a lot to say about it. We go to OT (occupational therapy) sometime and also to school and Ward 3 is where we sleep. Ward B is for the little ones. We go there to pick them up in the early morning, but they don’t come back for school in the afternoon...they must stay there to *slaap* (sleep).’

The different wards are designated ‘Wards A-F’. There are three female and three male adult wards in addition to Ward B (very young children, see Figure 19) and Ward 3 (bigger children, see Figure 20). As Gladwyn’s picture demonstrated, there were entrance gates, an audiology building, an x-ray building, a pharmacy, a kitchen, an OT department and school. One of the missing components in this drawing however is the XDR unit: a place children spoke of with curiosity, but never drew.



Figure 18: Scott's drawing, Ward 3

Scott, age 10, from Elsie's River explains his map (Figure 18):

'Yes – so this is the Ward 3. The bottom one (drawing) is the outside. It's yellow and red (tiles) on top (roof). The top one (drawing) is us, inside. We're in our beds, sleeping. We look like pilchards in a tin, *nuh?* And all the buildings look the same from the outside...just yellow and red. But inside they're different *mos*. The peoples with the bad TB, the big one – they're MDRs. Then there's the XDRs. You can't see them. It's a jail for them now.'

K: 'How do you mean it is a jail?'

S: 'It's like that, *mos*. We all have gates and buzzers and *dingus*. XDRs are so sick they could die! And also the men with the chains on from Pollsmoor come. I think they can get sick too.'



Figure 19: View of Ward B through fence of Ward 3, taken by Nkosi

Scott's explanation referred to the XDR ward, which, like many of the wards, is gated and equipped with a buzzer system. The XDR ward was very small, and it was rare to see anyone coming to and from the facility. It was situated beyond the kitchen and across the street from Ward 3. The lack of knowledge and experience 'in' the XDR ward lent itself to absence in the drawings of children in the map-making exercise; it simply did not feature. In addition, children were not allowed to enter into adult wards because of potential risk of infection. Unlike the childrens' wards, *any* personnel working in an adult ward was required to wear a mask at all times.

Verbal narrative animated specific buildings, but was absent in visual depictions based on lack of experiential claims. Although children were not permitted in adult wards, these buildings sat adjacent to the school, and some of the children's parents were also patients at BCH. Scott utilised a container metaphor when he likened the children sleeping to 'pilchards in a tin' (Lakoff & Johnson 1980). Comparing Brooklyn to a prison thematically galvanized BCH as an isolated mode of existence, a bounded place. Here, Sontag's (1978) disapproval of metaphorical romanticisation of TB is met with the complete antithesis. Scott's comments about the prisoners signified BCH patients who came from outside for treatment inside, refuting the notion that hospitals are bounded entities. The children were amazed to see 'real life gangsters' in handcuffs and leg chains shuffling to and from various departments with their warders. Scott's reference to the Ward being 'like a prison' lent itself to the metaphoric imagery of isolation and infection of BCH.

Scott employed a common metaphorical turn of language when he referred to the 'MDRs' or the 'XDRs'. A patient was labelled by the strain of TB they had and where they slept. This reifies what Sontag so abhorred (1978), a patient became their disease. The 'big TB' signified more severe forms of TB. Drawing on the size of TB inferred the type and severity of TB (Abney 2010). Those patients with XDR-TB, as Scott implied, faced the possibility of death. 'You don't even see those ones', as he said.

‘This is a hospital, not a home’ – Teacher Theresa



Figure 20: ‘Ward 3’, drawn by Shelly

I commence with a discussion of the understanding of space and security, routines and rules BCH patients were subjected to upon admission. A patient lifestyle is something that a child is indoctrinated into throughout their stay in the hospital. Constant reminders reinforced the idea that patient life was temporary, and children were not meant to treat the hospital as a home. Departure from home and admittance to BCH marked a new reality as a patient. For most children this process was extremely challenging.

Again, given that I met children here throughout the course of a year, their arrival dates and discharge dates overlapped, thus changing the group dynamic, understandings of time and, ultimately, the course of my research. Children remembered their arrival and discharge dates. Rosa took the photograph below (Figure 21) on the morning of Diepa’s discharge. Diepa lived at BCH for three years, from the age of 13. Unlike the majority of the photographs taken in the wards, this photograph captured personal possessions and the hospital equipment.

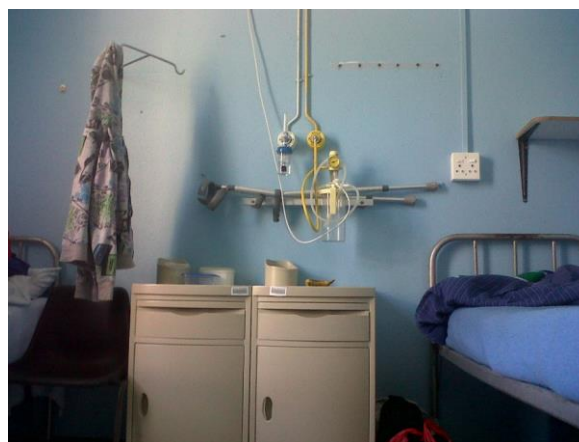


Figure 21: ‘I took this picture because you can see Diepa’s things. He’s leaving you see? And the oxygen machines are there to help Abi breathe. He can’t breathe proper hey? It’s the TB.’ -taken by Rosa

Admission and discharge dates were significant markers for children, their families and those responsible for their eventual treatment success. You could only know those who departed, not arrived. As Marissa explained to me one afternoon:

‘I don’t like new children coming in. It’s hard to know what they’re gonna be like you see? They can be naughty Kate. They can fight and sometimes they do fight. It takes too long (time) for them to come right.’

Sierra agreed:

‘I just hate new kids. I’m not even playing (lying). You see real quick the way they can go (the way the act). They better not mess with me, I’ll *klap*⁴⁵ them!’

Daily Routines: Standing Up and Drinking Your ‘Pillis’

‘You must wake up early and respect everyone. Bathe. Take your pills and eat your kos⁴⁶.’ –
Teacher Theresa

Every morning, children ‘drank’ their tablets, and prepared themselves for breakfast and school. Children washed (bathed) once, sometimes twice, a day: in the morning and in the afternoon, before supper at 4:00 pm. Children were constantly encouraged to be hygienic. As Nurse Jones asked them on a regular basis, ‘Cleanliness is next to?’ And their cued response: ‘Godliness’. Children ‘stand up’ at 5:00 am. They used this time to wash and prepare for school. Pills were ‘drunk’ before breakfast. The pill trolley wheeled into the main room and the table placed adjacent to the trolley. Nurse Jones or Nurse Lily distributed pills according to the individual patient files. Shortly thereafter, small plastic cups filled with a small amount of water were given to each child. A white vinyl tablecloth covered the pill table and soon its surface was populated by multi coloured plastic mugs and small translucent cups of pills. Children encircled the table and stood with their pills in hand.

Some children took longer ‘to drink’ than others, and each child had a specific strategy they used to drink their pills. Some drank the big tablets first, others the small pills. Some drank a certain number at a time, whilst others bragged that they were capable of drinking all their pills at once. Those who took longer to drink inevitably slowed the progress of their day, and that

⁴⁵ Afrikaans: Smack, hit

⁴⁶ Afrikaans: food

of others. Others who were caught ‘fake vomiting’ or who refused to take their pills were not allowed to leave for school or have breakfast until they did so.

‘God is great and god is good, thank you lord for all our food. Amen.’

The children finished this prayer and commenced eating their *kossie*⁴⁷. Older children set the tables on the stoep with a single serviette and a spoon per child. The nurse or the cleaner on shift carted out the food trolley and food was distributed, plate by plate. Breakfast usually consisted of a cup of tea with milk and any of the following items: anchovette fish spread or butter on toast, scrambled eggs, porridge, oatmeal, fish sticks, chicken sticks or hard-boiled eggs. During the meal, talking was not allowed. Often, children were admonished if they spoke and ate at the same time. ‘I only want to hear the sound of your spoons’, said one cleaner. ‘You mustn’t speak nuh? I want to see those plates clean.’ In other instances, children were encouraged to eat more slowly. ‘There’s no food at home, you can see sometimes, *mos*’, Nurse Jones said one day. I watched in amazement as Lolly cleared her plate in a matter of minutes. The other children at her table laughed. Lolly, who spoke in Afrikaans to me (although she understood English), became embarrassed. An older girl observed, ‘Yoh, stop panga⁴⁸! You mustn’t make so! It’s rude man!’ The Lord’s Prayer marked the end of every meal and simultaneously, at different pitches, tones and mumbled recitations, the prayer dribbled out, and children cleared their plates on to the steel trolley.⁴⁹

‘Our Father, who art in heaven,
Hello (Hallowed) be thy Name.
Thy Kingdom come.
Thy will be done on earth,
as it is in heaven.
Give us this day our daily bread.
And forgive us our trespasses,
as we forgive those that trespass against us.
And lead us not into temptation,
but deliver us from evil.
For thine is the kingdom,
The power, and the glory,

⁴⁷ Afrikaans: food

⁴⁸ isiXhosa vernacular: To eat in a rude way, generally eating too fast.

⁴⁹ Prayer was an important marker, but I do not make mention of moral citizenry or cultivating the moral body here. See: Fife (2001), Bornstein (2005), Piot (2010) and Fassin (2011) for excellent sources

For ever and ever.
Amen.’

The children brushed teeth and washed hands, and we slowly made our way to the school, stopping to fetch Ward B children en route. School commenced at 9:00am. Recess was from 10:30 -11:30 am after which point lunch was served in the ward. Anywhere from 12:00pm, 12:30pm to 2:00pm the children played at school. Dinner was served promptly at 4:30. Dinner and lunch meals aimed to provide a starch, protein and carbohydrates and vegetables. The second bath of the day (or in some cases the first) commenced at 3:00pm. Those who needed injections were sent to Ward B. Linens were changed regularly to prevent transmission of illness via infected (old) linens, and the ward was swept and mopped by cleaning staff three times in the day. Windows remained open (see Figure 22), no matter the weather outside, thus increasing ventilation, whilst UV light and extractor units furnished every room⁵⁰. At 7:00pm soup and tea was served, and at 8:00pm the bedtime prayer was recited and the children prepared for bedtime.



Figure 22: ‘This is my bed in the corner’ -taken by Gabi

⁵⁰ See Parsons et al (2010), Escombe et al (2009).

Diagnosis: ‘Chasing the contact’

‘This is really a mess’⁵¹

I’m sitting in on my first patient review session. I am inexplicably nervous.

A large moveable light screen is brought out onto the stoep of Ward B. The sound of babies crying permeates the space. Chest x-rays are placed on the light screen, and some are passed around. The medical students are asked questions and often fumble through their answers. The group reviews each newly admitted patient, in addition to two month reviews of existing patient, exhausting a list of different criteria: preliminary symptoms, a trace contact, diagnosis, social circumstances, and current treatment regime. The social circumstances which are discussed immediately grab my attention: type of house (brick or otherwise), location, number of people living there, how many adults, how many children, who is employed, HIV status, trace contacts and trace cultures. If there are any specific issues with the social background or physical impairments, social workers and occupational therapists were present to address their progress with each individual child concerned. (Field notes)

On Wednesdays, every week, I attended a patient review session. New cases were reviewed and existing patients given a two month review. Professors Roberts and Dudley accompanied the session every week, in addition to social workers, attending doctors (like Dr. Early), occupational therapists and psychologists. This group of individuals discussed each case in order to arrive at diagnoses, calibrate medicine dosing, and follow up with psychologists, social workers and occupational therapists. They were, to extend the notion from Mosse (2004 ci Human 2012), an ‘interpretive community’. Interpretive communities of varying scales aid in establishing protocol and treatment models for paediatric TB (Human 2012).

‘Prof’ (as Professor Roberts was commonly referred to) ran an ongoing study which attempted to better define ‘appropriate’ paediatric drug dosing. At the time, paediatric doses were based on body weight, but not necessarily the appropriate ‘type’ of drug. The majority of TB drugs were developed in the mid-20th century, and have not accounted for the differences in children’s bodies. Dose deceleration presumed that a child’s body was the miniature version of an adult’s body. Prof believed this was a faulty assumption. He explained how the water

⁵¹ (in reference to paediatric TB in the Western Cape) - quote from a doctor attending at BCH.

content, the basic physiological structure and organ function of children's bodies differed greatly to those of adults. Prof and his team tried to reduce the length of hospital stay for paediatric patients through developing better and *more appropriate* drug therapies. Some, but not all, of the children at BCH participated in his study.

After the first month of attending these weekly sessions, there were patterns which continued throughout research. Macroscopically, migration from the Eastern Cape contributed to the number of patients who sought treatment, and the spread of TB. According to the doctors, Eastern Cape migrants normally consisted of 'bad referrals and no information' from clinics or other health care facilities. The lack of information resulted in many 'missed opportunities', delayed diagnoses, and in extreme cases, the physical detriment of the child. Ideally, one traced an individual patient's movements through a constellation of facilities; the local clinic, Tygerburg Hospital, Red Cross Children's or Groote Schuur were names I heard often. In regard to African immigrants who lacked basic patient documentation (an identity document or valid visa), there were a litany of questions, without answers. A researcher from Worcester asked, 'Sometimes, there simply are no papers. It's like the patient never existed. What do you do with that?'

The review sessions highlighted the nature of TB transmission and that the treatment methods available were geographically dependent. If the most extreme cases were treated at BCH and D.P. Marais⁵² in Cape Town on a provincial basis, the movement of people nationally *could* be restricted if they tested positive in Cape Town metropolitan area. The movement of people was restricted to the TB their body. Migrant populations therefore received treatment in the Western Cape and eventually returned to the Eastern Cape TB free. This phenomenon bore the imprint of history, labour base, and severe lack of adequate medical services to cater to infected individuals⁵³. As I came to understand over time, Eastern Cape facilities were not equipped to work with TB patients.

Paediatric TB presented myriad diagnostic and treatment challenges, often exacerbating dire circumstances. Dixon's (2012) work substantiated the ambiguities and elusiveness of paediatric TB diagnosis and the 'extra protocol' doctors frequently employed. Sometimes TB was mistaken for pneumonia, or a series of TB meningitis symptoms were read as the flu. One

⁵² An adult TB treatment facility in Retreat

⁵³ See Packard (1989)

such case was a young Zimbabwean child, who, after three months without a clear diagnosis, was paralysed with TB-M and spinal TB. Professor Dudley added, ‘If you’re in a clinic in Zimbabwe, they’ll give you a Panado and send you home.’ There were many potential diagnostic pitfalls, and it seemed doctors were acutely aware of their *own* uncertainty in the diagnostic processes available to them. Sometimes there was no evidence for a Mantoux test⁵⁴, no BCG⁵⁵ scar on the patient’s body. Prof appealed to the medical students:

‘We must look at the *whole* patient and their circumstances. If you see a kid with high temperatures, persistent fever, vomiting, and constant headaches, get the test done. Kids don’t have stress-induced headaches like adults do. It’s *not* the flu. These are classic symptoms for TB-M.’

‘Believe nothing they tell you, and only half of what you see’ – Prof Dudley

...the bodies of children are the material to be read; in a bid for more visible indicators, signs, symptoms, something. (Field notes)

After each review session I felt depressed, overwhelmed and ultimately confused by what I perceived as a system entangled in ‘thick’ bureaucracies. Surrounded by those I considered to be biomedical superheroes, I could only fathom the implications nationally and worldwide for inconsistent practices at the ‘ground level’ and children getting lost in the matrix. Inconsistent notes from the referring hospital or clinic and ambiguous or poorly documented patient histories were the ‘norm’. Such thick bureaucracies permeated and entangled routinised procedures which created further delay, in what was considered (for all reasonable purposes) an urgent situation. Sometimes hospitals failed to follow up on the individual patients, whether it was for prophylaxis or a routine exercise. When a child was diagnosed, or if the TB contact was known, the entire household was asked to come in and test. This routine procedure did not always transpire, and some children were continually exposed without access to drugs. If there was a child under two years old in the home, it was vital to get screened and go on preventative prophylaxis. When processes like these did not occur, doctors were forced into an ambiguous

⁵⁴ Mantoux test-basic test for TB-tuberculin is injected on the arm and the reaction is measured in diameter

⁵⁵ BCG vaccine leaves a pocked scar- a clear way to assess whether child has received vaccinations or not as the scars are generally visible.

and often helpless situation. Sometimes they didn't know *exactly* what they were treating; test after test was inconclusive. They carried out treatment anyway.

'Messy' circumstances and thick bureaucracies confront the biomedical 'ideal'. 'Exceptional' circumstances do not fit neatly into the efficiency, rational, or logical progressions that biomedical standardisation is rooted in. At BCH there were *many* exceptional circumstances, social and economic hardships that influenced every single patient and their individual situation. Oliver Human's (2012) work elegantly problematized such fissures. Human discussed the role of protocol in modern medicine, and its implications for patients and practitioners alike within the South African context. One of the patients he presented was a young boy named Jonathan who was HIV-positive. His doctor looked at his skin, the rings around his eyes and the wasting of his body, and knew, without microbiological samples, that he had TB.

My data demonstrated that doctors grappled with and confronted the constraints of life in their practice every day at BCH. Protocol only existed in an ideal scenario, and yet life for many can hardly be described as ideal. Human argued, 'In its description as a cognitive-scientific enterprise, the *practice* of medicine has thus been estranged from the practical, contingent reality of life (2012:226 emphasis mine). Rather, when Human offered Jonathan's story, the doctor drew upon a capacity philosophically known as *phronesis*. 'Phronesis describes action related to contingency and the ability to adapt universal rules to particular circumstance (ibid: 229).' Although Jonathan (like many of my patients) was unable to produce sputum, his doctor knew without testing him that he had contracted TB. Later, tests confirmed this.

Human theorised further that, 'Isolated traits or symptoms have no inherent worth or value to the doctor; what is important to the doctor is the relationship between the different parts of the whole that define which symptoms are important and which are not' (ibid: 236). The material aspects which impacted upon the child, their diagnosis and their home life were the factors which were considered in *every* case by the interpretive community at BCH. Nothing could be taken in isolation because every factor constituted a different, not separate, part of the whole patient. When Prof asked his students to see 'the whole child', his plea was for them to utilise *phronesis* to the best of their ability. Arguably, one's *phronesis* evolves alongside experience and familiarity with TB and the variety of factors that are characteristic of the South African

state medical system. In her gripping ethnography of cancer patient experiences in an oncology ward in Botswana, Julie Livingston's argument is similar. She explained that, 'improvisation is a defining feature of biomedicine in Africa' (2012:6). Her research paralleled the structural challenges patients and doctors experienced from diagnosis, treatment and eventual cure at BCH. Uncertainty was always present, improvisation was a strategy to cope with the unknown.

Often times contact cases from Eastern Cape cannot be traced. This paired with inconclusive diagnostic tests is very problematic. The doctors added too, that the more severe the TB, the higher likelihood of relapse rate; meaning that there is a higher likelihood the patient will become sick again if they default on their medication. In addition to this, the more extensive the disease within the body, the more expensive (and longer in duration) the treatment and access to treatment will be. (Field Notes)

Professor Dudley added, 'The final proof in the pudding is to see if a patient relapses-if you don't do that- *it's anyone's guess* (how they get re-infected or become ill again).' The uncertainties mounted with every review session. 'TB is curable, but the late diagnosis is often to blame...there are many missed opportunities...especially when parents or children are not screened properly' explained Prof.

Retrieving the necessary information in order to diagnose a child with TB is equally arduous. Various biopsies, lumbar punctures, sputum samples, gastric washing (gastric lavage), tissue cultures and pus swabs are different diagnostic techniques for different types of TB, and are not necessarily successful in isolation. Dr. Early described how the angle of an x-ray can influence a diagnosis, resulting in a different 'reading' altogether. A technician may have rushed the process, or the child squirmed while the films were shot. Still, Prof seemed to prefer cultures of sputum as the next best diagnostic technique. He explained:

'Do everything you can to get a culture, because oftentimes children's x-rays can be very misleading...Whether it's a biopsy through a needle or a (gastric) wash. Getting that evidence saves the doctor sleepless nights and concern...otherwise we just end up with the worst-case scenario. Maybe in three to four years' time we'll have a new regime...but 18 months in a hospital is a long time...and with current drug susceptibility the outlook is not good'.

Marissa

During the research Marissa was prohibited from staying with her mother, father and sister in Blikkie's Dorp⁵⁶. Their government-provisioned home was (as the name of the settlement implies) a tin box. On my many visits, I noticed difficulty breathing inside the house, there was little to no ventilation. Marissa's mother showed me the humidity building on the ceiling in the wintertime, 'Look at all this wet Kate, it makes the clothes smell *miff*' (musty). In the summertime she would remark on the unbearable heat, 'It's more like a microwave in here than anything.' The social worker, Victoria, prohibited Marissa from staying in Blikkie's, deeming the conditions unliveable.

Ironically, Marissa continued to stay with her grandparents and uncle when she was given leave every other weekend, although her uncle was her TB trace contact. He defaulted on treatment and had infectious MDR-TB. 'It makes no sense to me', Marissa's mother told me. 'That man is so sick and he won't listen. I don't want my baby getting sick again.' Unlike other patients, Marissa encountered no issues with drinking her pills. Taking her pills was in Marissa's words, 'a way out of here'.

Rosa: 'Many missed opportunities'

In May 2009 Rosa was given 6 months of TB treatment, but after 2 months she was still testing positive for TB. After 6 months she was still symptomatic and developed an infection. Her local clinic continued with a TB drug called Rimactizid but did not follow up on sputum sampling. In 2010 she developed MDR-TB and entered BCH with many drug sensitivities. She was on Amikacin injections for 6 months. After 9 months of DOTS at the local clinic and consistent two month check-ups with Prof, her situation had not improved. Her mother admitted that Rosa refused to take her medicine. In September 2011 she was re-admitted to BCH for MDR-TB therapy with multiple drug sensitivities. For a child, this was an extreme circumstance. Her brother and father had TB and three of the children in the family of 8 were taking MDR-TB therapy.

As Prof explained, there were 'many missed opportunities' with Rosa's treatment. She developed issues with her hearing because of the Amikacin injections, however her hearing post Amikacin had actually improved which was unusual, because generally children lose their

⁵⁶ Afrikaans: 'Tin (box) Town'

hearing permanently. She also developed secondary hypo thyroidism as a side effect of the TB drugs.

Rosa's lack of adherence and resistance to certain drugs contributed to her becoming an MDR patient. The doctors told me that she was most likely re-infected, but 'it's hard to know for sure.' Even though her mother had been adamant that she had been taking her medicine, after three weeks back at BCH she was constantly nauseous and later admitted to stopping treatment because the side effects were 'too much'.

At the time of research, Rosa had been on 15 months of MDR-TB treatment. She and Sierra were best friends.

Sierra

In Sierra's case, she was considered 'lucky' because she came from a very stable family in Hanover Park. Both her mother and step father were health care professionals. Her step father was working as a Physician's Assistant and the doctors attributed her parent's vigilance and participation to her eventual institutionalisation at BCH. Contrasting Sierra's explanation with patient review information provides two different registers to speak about TB, but it also exposed a disjuncture. As a researcher, it was difficult to establish whether or not children's explanations of their disease was congruent with hospital records and information from review sessions. In many cases, a child's explanation dramatically differed from the information provided by a social worker or a nurse.

Sierra first had TB in 2009, and the only information provided in her patient records was that she had taken treatment for 6 months. There was no trace contact on record. Initially she complained of a high fever so her parents took her to a private clinic. Her chest x-ray was 'close to normal', but the diagnostics were never submitted. Her fever subsided and she was given treatment. Eventually the clinic stopped treatment because her condition had improved. However, she felt 'not right', but returned to a different clinic. They ran a series of radio isotoping diagnostics and bone marrow biopsies. The samples were eventually sent, but both of the sputums provided were negative. Sierra was then admitted to a private hospital, where a sinus drain was inserted in her neck to drain off the mucus secretion. According to Prof, 'Luckily for the child, she developed a node on the clavicular left hand side'. This was a significant visible indicator for further diagnostics. A lymph node culture finally confirmed TB.

At 10 years old, Sierra was admitted to BCH in March 2012. She was finally diagnosed with MDR-TB with an INH mutation and ethionamide resistance. Sierra's TB contact, a friend of her grandmother's, had passed away from MDR-TB infection. When I asked about the drainage from her neck, she explained:

'It's *naar*⁵⁷. Nurse Jones has to dress it every day. She tells me that the TB is different for everyone, and this way the TB leaking out of the body and it's a good thing it is happening.'

Sierra's story paired with the patient review information demonstrates the constellation of medical services an individual family will patronize in order to receive successful diagnosis and treatment. This was another way that Sierra was 'lucky'. In comparison to the majority of the children at BCH, her family possessed financial means and medical knowledge. This translated into a stable family environment. In patient group 2, Carlito, Themba and Gift were polar opposites. All three boys came from abject poverty and in the end were placed with social services. As Dr. Early explained on one occasion:

'Most of the families we have issues with is when the mum cannot care for her child – or doesn't want to. We try to find someone in the extended family. If not, we must find placement for them with social services. It's part of the problem of being on the hospital side of things, you know, we're so far away. I refuse to release or discharge a child to uncertain circumstances. I'd rather keep them here until we can find a suitable placement.'

Themba

On the 15th of December 2011, an aunt took Themba for the long weekend and never returned. The social worker, doctors and nurses were concerned and tried to trace him. There were no working cell phone numbers and the residences listed were unoccupied. The majority of his tests were inconclusive, but he had been treated as an MDR-TB case. When Themba returned to BCH in early February, he had TB symptoms all over again. During his absence his essential medicines were finished. I watched in agonising tedium as he re-learned how to take his medicine. The laborious process of swallowing a handful of pills, only to vomit them up again.

⁵⁷ Naar can mean gross, disgusting. It is also the word for vomit.

Scott: ‘lucky to be on treatment’

Scott’s mother had been on an alcohol binge. She left the ten year old boy in the care of his father and uncle. He presented at a local clinic with a fever and a headache. He was diagnosed with Pulmonary TB and TB-M stage 1. They did a gastric wash at Paarl hospital and they also found the trace contact: his 22 year old brother who had drug sensitive TB. The brother was diagnosed in January, took his treatment, and completed the course. Scott’s x-rays were positive, but there was no record of a Mantoux scar or mention of anything else. Of the minimal notes from the referring hospital, one stated that the ‘child is a defaulter, taking his pills one week off and one week on’. During his initial patient review session, Professor Dudley looked up from the file and chuckled, ‘It’s not the child’s fault. He is defaulted *upon*, he is not the defaulter. His parents are at fault, not the child’.

Professor Dudley reviewed the file in front of him and paused to explain an ambiguity with the spinal fluid extracted through the lumbar puncture, or ‘punch’ as it is known by children.

‘Sometimes – as is the case with this boy – the sample of fluid will look almost normal. We must look at the child as a whole. What are we seeing? This is exceptionally important with TB-M. If we can diagnose early, we will prevent paralysis, brain damage, all sorts of very bad results from the TB-M’.

He continued:

‘This boy is lucky he is on treatment and they exhausted different diagnostic techniques...anything to prevent stage 2 or three Meningitis. If there is a diagnostic delay it can result in brain damage, paralysis or potentially death...the individual will not be active in society’.

Phelo

Phelo presented at the Red Cross Children’s Hospital. He was there with his mother to see the dermatologist for eczema, which is characterised by dark spots all over his body. The dermatologist took note of this and Phelo tested positive for MDR-TB. He was classified as marasmic⁵⁸. Once admitted to BCH he began his treatment for MDR-TB.

Phelo’s mother was described by staff as being ‘a difficult, stubborn woman’. Dr. Early implored her to test Phelo’s two year old sister. She also told Dr. Early at one stage that Phelo

⁵⁸ under weight and prolonged lack of sufficient nutrient uptake

must ‘just stay in the hospital the entire time (for the full 18 months) and not just 6 months’. There seemed to be very little means to care for Phelo. Eventually, Phelo’s little sister was also admitted to BCH Ward B for treatment.

Gift

Gift, like many others, was admitted originally into Ward B after a stay at Red Cross Children’s Hospital. After he was no longer infectious, he moved to Ward 3.

Gift lost his mother when he was three years old. His father had relocated to Kimberley, and Gift had stayed with his grandmother. Khaya, the social worker, explained that his grandmother and her boyfriend were alcoholics. He frequently spoke of Gugulethu, but also implied that there was little, if anything, to eat. His sister operated a small *hokie* which also functioned as a shebeen. He told me that, ‘...the old people go there and get *dronk* (drunk)’ and imitated them falling on the ground, unable to get up.

Gift had developed hearing loss because of the Amikacin injections and so those medicines were ceased in April of 2012. His audiology reports showed a severe drop in hi frequency recognition, and sometimes Gift would have a hard time hearing me when I spoke to him.

In the following section I discuss the medicine regimes a paediatric patient takes, their side effects, and how children’s bodies literally became ‘bodies at work’. There was an acute understanding of the pharmaceutical regimes each child ingested, its negative side effects and personal recognition of the amount of pills consumed daily: also referred to as the pill burden. The theme of pill burden ties into the overall conceptions of burdening and unburdening different bodies. Medicines were considered to be a burden; their effects on a child’s body, their mental and emotional state was all-encompassing. Yet, the medicine, their cost, and the benefits of being a patient at BCH often balanced these physical costs or burdens to the individual child. As previously demonstrated, many of the BCH children came from homes and families who were unable to care for them whether they were sick or ‘healthy’.

Medicinal Meals

The presence of medicine in a paediatric patient life was overwhelming. Pills came in a variety of different shapes and forms, colours and applications. In addition to routine procedures, pills were the bedrock of patienthood. Treatment success hinged on one’s ability to take pills and to do so on a consistent basis. In her sophisticated ethnographies of China, Judith Farquhar

transports her readers to a modern nation state grasping onto Mao-era corporeal practices (2002). When Farquhar writes of ‘medicinal meals’, she speaks to the ties between politics and eating – the consumption of certain types of beneficial meals associated to the cultivation of bodily health. In a cosmopolitan setting, Chinese patrons enjoyed a host of delicacies imbued with Chinese medicine. Here, embodiment as a paradigm shifts from the idea of phenomenological pursuits, to grasp at the practices and interactions that make a body, socially constituted. Food, appetites and eating are the domain of inquiry. But what if you are not consuming a meal constituted of food, but one of multi-coloured pills of various shapes and sizes? What if the (food) meal is only secondary to the main course of medication?⁵⁹ Unlike the culinary and medicinal sensuality Farquhar invoked in her work, the ‘medicinal meal’ at BCH implied life or death. Politics and the ‘responsible patient’ took on an entirely new dimension with every pill a child consumed. Pill taking, pill ‘burden’ and responsibilization (Robins 2006) are thus intertwined components which help produce a paediatric patient at BCH.

One Pill, Two Pill, White Pills, Red Pill

‘My job is to drink pills. I have to do a good job so I can go home. And it’s everyone’s job, but you must do this.’ – Zwai



Figure 23: The main room in Ward 3

⁵⁹ See Schmidt (2012) for links between diet and TB in Namibia

‘The TB don’t play. If you don’t eat it, it will eat your insides. That’s why you must eat to fight it off’ – Rosa

Medicine, and the consumption thereof, became synonymous with treatment success, as well as an ideal ‘good patient’. TB has been equated with a type of consumption; something that engulfs and consumes the bearer of the disease. Yet, children used metaphors associated with the notion of consumption in relation to their medicinal regimes as they did in describing the ways that TB consumed the body. Fundamental to ideas around consumption was the consumption of pills. Here the words pillis, pills, drugs, meds are employed interchangeably because these were the names used by children and nurses. Children who failed to ‘drink’ or ‘eat’ their pills were considered unruly, trouble makers, or problematic. Medicine was administered twice a day: at 8:00 am and 8:00 pm in the main room in Ward 3 (Figure 23). The pill trolley was always ‘out’ when I arrived in the main room of the Ward (see Figure 24). Children waited until their name was announced to gather around a white vinyl covered table. A pitcher of water and monochromatic plastic cups waited for those in need of extra water (Figure 25).



Figure 24: ‘I hear the tablet trolley coming when I’m sleeping, and I know.’ – Nkosi



Figure 25: Gabi's tablets on the pill table, taken by Rosa, Ward 3

I normally attended pill drinking time in the mornings, however after my first three months, Nurse Jones asked me to wait on the stoep because she felt I was distracting the children. Children informed me daily who vomited as a result of their medicine, and who had not. Equally important was to persuade those who experienced pill 'anxiety' to take their medicine.

Some vomit was identified as 'real' or 'fake' vomit. The real vomit indicated the colour of pills: it was bright orange and yellowish in colour. Children constantly complained about feeling 'naar' and wanted to vomit as a result of the medicine. If a child did purge the drugs, they had to take them again. Some nurses were more tolerant with slower drinkers, but others were less so. Nurse Jones admonished them if they did not 'drink their pillis quickly', or alternatively, she celebrated those who could take their medicine all at once. Some nurses made the children drink their pills before eating their food. Others adjusted the administration of certain nausea-inducing drugs after a child ate in order to help 'keep the medicine in the tummy'.

Some children were spoiled by their parents during their weekend visit. Eating three days' worth of food that a 'TB tummy' is not accustomed to can have detrimental effects. Eating high fat food, a lot of meat, or consuming an excess of 'luxuries'⁶⁰ was dangerous for digestion as well as the absorption of drugs. Often children returned from weekend visits unable to stay awake, very nauseous, or carrying food they would later stockpile in their locker. Other times, it was unclear if children were getting their treatment at all while they were home.

⁶⁰ Luxury foods are sweets, cool drink, any type of food which is not easily attainable or considered 'healthy'.

One Monday afternoon I was speaking with Gabi. We were discussed the weekend and what she did at home.

G: 'and so I went home for this weekend nuh?'

K: 'How was it?'

G: 'Nice...my mummy bought me sweets and nice things to eat.'

K: 'OK, that sounds pretty great! Did you play a lot?'

G: 'Yes, of course I did!'

K: 'What else did you do?'

G: '...No, that's about it Kate. And I didn't take my medicine hey?'

K: 'Oh...why not?'

G: 'I told my mummy she must take it down from the cupboard. She put it so (indicates with her hands above her head that the medicine was placed out of her reach). I kept asking her to fetch it for me. She didn't do it. She lied in the bed and said 'Gaan (go)!' and so I left her room. My mummy doesn't hear well most times.'

K: 'What do you mean she doesn't hear well? She has a hard time hearing?'

G: 'No...My mummy doesn't *listen* well. I tell her I must take the pillis and she was sleeping- she says 'Gaan! Go- you must go. I'm resting'. It's like that.'

Gabi did not receive her medications the entire weekend. When she arrived back from her weekend away, she was sick with flu-like symptoms and a runny nose. This conversation prompted a frank appraisal of the challenges children face at home and getting access to their medicine. Although Dr. Early and the nurses explained to family members and guardians the medicine regime, and the importance of taking the medication timeously, these concerns often went unheeded. Nurse Lily explained:

'Children know their medicine. They know it better than anyone else. Better than their parents, sometimes better than nurses! One time I can remember there was a new nurse working here and the children were correcting her because she accidentally gave the wrong one (pill). No, they know.'

Nurse Lily and I developed pill charts for each child (Figure 26) in order to help them 'learn their pills' by more than colour or size. The children could identify the colours, shapes and sizes of the pills, but did not know their pharmaceutical name. If a child could not access their medicine, they could potentially explain their treatment course to a health care professional at

their local clinic. We developed the pill charts with each patient. They would draw their pills, colour them in and write the number and formal name next to each entry. In this exercise, Rosa contributed through taking pictures of what she felt was important for my research.

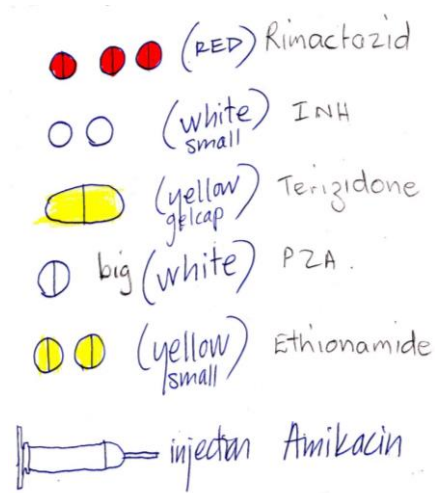


Figure 26: a patient's pill chart

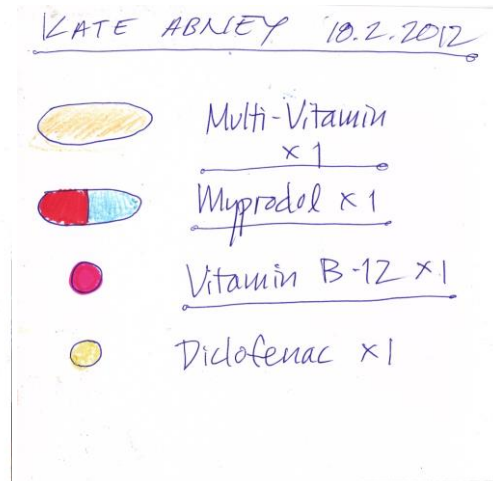


Figure 27: Kate's pill chart

I also made a pill chart (see Figure 27), because for a time I was drinking 'my pills' alongside the children in the mornings as a way to make them feel better about taking their tablets. My pill chart is on the right hand side, and another pill chart (Figure 26) is on the left hand side.

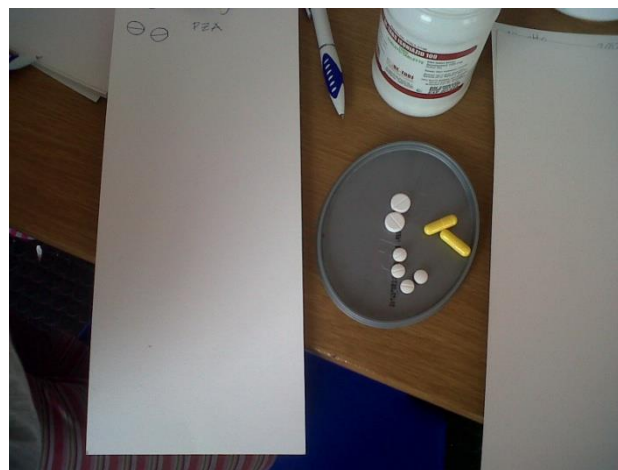


Figure 28: 'Counting out your pills' - taken by Rosa

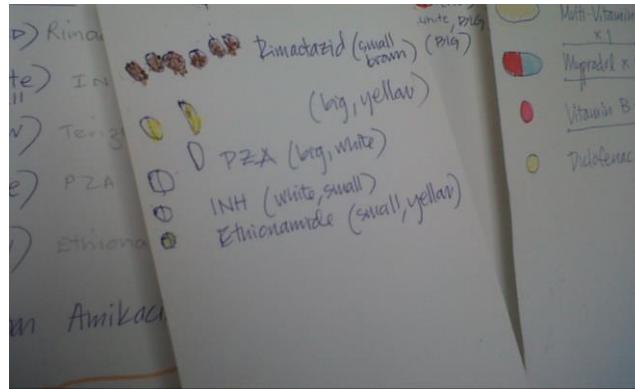


Figure 29: Pill charts - taken by Rosa



Figure 30: 'pills'- taken by Rosa



Figure 31: 'Important stuff and Kate's red nail polish' - taken by Rosa

R: 'I took these pictures⁶¹ - it's good for your research nuh?'

K: 'What do you mean?'

⁶¹ See Figures 28-32

R: 'Well - you need to know this stuff man.'

K: 'What do you mean Rosa? About the pillis?

R: 'Yes. You know *mos*. It's like these are the things that will save my life. That's important nuh?'

K: 'Yes, I agree. It is very important.'

R: 'So you see titti (sister). So I'm not going to die. If you don't drink, you die.'

Some children, like Rosa, had defaulted before, but assisted others, like Gabi, in taking their pills, although Rosa had her own hesitations about taking pills. Although some doctors thought children were not capable of defaulting, there were many times I saw child patients refusing to take their medicine, hiding it, or tossing it into the refuse bins when no one was looking. Others, like Phelo, would try to flush their pills down the toilet. Gabi refused to take her pills sometimes, but opted for spitting them back up. Nurses knew this was not 'real' vomit, because the pills had not started breaking down. Refusing treatment was not uncommon at BCH, but it took different forms. Nurses working in the adult wards would speak about the amount of pills they would find after lockers were cleaned by staff.

Nurse Lily explained:

'Yoh, Kate. These adults! They can be so difficult you know. They'll hide the pills away and just stay sick. They're killing themselves, *mos*. Sometimes you think they just want to stay sick.'

Teacher Grace thought that children were looked upon as role models:

'Adults ask me, "Hey, Are these children also sick?". I explain they are, and they take the same pills as you. I think it helps them. Because then they know that if these little ones can take these pills, they can too. They (the kids) are an inspiration. They're role models like that for adults.'

Each child took different amounts of pills. The amount was greater if they, like Gift, Carlito, Phelo and Themba, had an additional HIV infection and were taking HAART. Some children took close to 30 pills of various shapes, sizes and colours every day. A standard six month TB course costs US \$21.00 per patient and is taken over the duration of six months⁶². A standard MDR-TB treatment takes between 18 and 24 months to complete per patient, and can cost

⁶² See Zaleskis (2005), Ecks and Harper (2013)

anywhere between US\$4,400 - US\$9,000 per patient⁶³. Again, based on numbers alone, the more extensive the disease, the more costly the treatment in both time and money.

‘We have many eyes here’

I had the following conversation with Nurse Lily in a formal interview. I include it here to demonstrate Lancy’s arguments (2012) about agency and the constraints specific to patient life at BCH. Ultimately, children were indoctrinated to a specific set of routines ordered by medicine. Pill-drinking was imperative to being cured of TB, although some children employed strategies to avoid taking their medicine. According to Prof. Dudley, the onus of responsibility was on the adult to provide medication. By this logic, children were not capable of defaulting, they were *defaulted upon*. Gabi’s weekend visit highlighted this earlier in the chapter. In the following conversation, Nurse Lily eventually relents and explains that although children can make the agentic choice to not take medicine, if they are within the hospital, nurses or other staff will ensure the child takes the medicine. Ultimately, children do not have a choice, thus proving that *agency* is *not* freely available to all.

K: ‘Do you think children have an easier time to adjust to a new environment like BCH?’

L: ‘I think for children – if the nurse makes it happy for them, if they take the time to...it’s easier. The children have a choice though – and they will make those choices. If the child doesn’t want this pill- or that pill...you see- they will make up their own mind. Even with food – if they don’t want it – we tell them they must...and they must.’

K: ‘So they don’t really have a choice?’

L: ‘They have to. The children is more that they must do and listen...and it’s one of the reasons children are so happy to go for the weekend. They get spoiled – you can do anything any time...but for the children it’s much more harder I think...you are not their mother, but with the adults – it’s nice – they can go out much more often. With adults – they usually come with money to spend by the tuk shop – children don’t have that freedom....if parents haven’t got money? There’s no money to buy luxuries at the shop you see? So it’s difficult for them. Adults can say “no I’m not eating that.” And they don’t...children must eat what is there. It’s not so much that it’s hard for them...they just have to listen to the nurses or doctor or the policy of the hospital...they don’t have a choice. Maybe you say like here in South Africa – everyone has freedom to choose and and and...Not they. *There’s no choice for them*. Adults can go and sit under that tree there. These children cannot. Their lives are regulated you could say.’

⁶³ See Zaleskis (2005), Ecks and Harper (2013)

K: 'So what do you do when you have a child who doesn't want to take their pills?'

L: 'You speak to them...you ask them...I say- 'Listen here, what tablets you want? I first ask what's the problem? Are you nauseous, or are you feeling too tired? What's the story here you see? Then they'll say – Nurse – this tablet is making me so naar, and I say – ok fine...I'm not going to give you this tablet now – but you can take this...I ask them to try the tablets one by one... I just say keep trying them and soon enough they realise they're almost done with taking them...it goes quickly if you take the time to help them... They also know that if they don't like water with the tablets- we won't do it. In the day we used to give them milk with the tablets...Especially with the yellow tablets...they make nauseous children. If they are extra nauseous – doctor will give them a pill to not being nauseous anymore...But these pills are strong drugs and they are so bitter too...And we ask the night nurse to do the same. If they don't want to drink the tablets outside of that – there is a way...The child must try by all means to take the medicine though...'

K: 'And then what do you do when children default? Does that happen?'

L: 'Yes – many people don't believe they can...they can...like with Rosa – we asked her what was going on. And she said it wasn't her. She said it was her parents or whatever on the farm with them...from start here...she always took those pills...so maybe it was the adults not taking responsibility for their child's treatment every day...I don't know. But also with Phelo – he too – he takes those pills – but his mum refuses to help him with them over the weekend...it's not that he is so sick either – there's just no support. If there was support he wouldn't be here. They picked up on the fact that his mum wasn't participating and they said 'no' – you're going to BCH, that's what it is.....but with the TB and HIV and lack of parental support – yoh. Recipes for disaster...What we do with children that have family that don't go...we see this stuff happening on the outside – and they must come back or just stay...like the other child – Gladwyn – he too. Wasn't taking the pills – and he has the support at home – a good family too. But this business of not taking the pills...no, it can't turn out well if it carries on. If the mother is not us – and by that I mean us here at BCH –then we know *mos*. We have many eyes here. A child is not going to drink quickly a tablet he didn't like...yeah – so we just have them to stay over...little bit of cool drink, a little bit of anything so the tablet can go in. You see?'

The conversation continued and I ask about HIV awareness amongst Ward 3 children.

K: '...And children that have the virus? Do you think they know they have it?'

L: 'They know...if you are even as young as seven years old, you know. The children know – but I don't think they know it (HIV/AIDS) can kill you. They know to take the 'other' tablets, and you are sick...but I don't think they think they will die. They see the other pills or they are taking the second round of pills in the afternoons...the children see that – they see that maybe so and so is taking different pills or at a different time and they put it together...but with the TB drugs – they know it can kill you if you don't drink them...with the other (HIV) they don't know that...but not with the under 7s, only if you are 7 and up are you aware of this I think...some of them exactly know – if I don't take my tablets I can die. Some of them. The

other tablets – they don't know about that. They don't know the broad implications...but they know the tablets...'

One afternoon, the Children's Radio Foundation was facilitating a workshop with the Ward 3 children. We had already learned as a group how to record audio files, use the microphones safely⁶⁴ and had attempted doing interviews with each other. That afternoon however, the kids wanted to focus on talking about the negative side effects of their pills. The following excerpts came from this session. The narratives were kept in the sequence and flow of the workshop. Some patients featured more often because some children were more enthusiastic about sharing and recording their experiences.

Gift: 'I'm now staying in Brooklyn Chest for TB, MDR. I drink 15 tablets and two grey ones three yellow ones. Hmmm. And four small ones. Yoh (laughs). Yeah. I'm not crushing them (into a powder, mixed with water) here. At home I am crushing them. Here I take them one by one. Maybe I take an hour to drink them all.'

Sierra: 'I drink 3 yellow, two grey, five white ones, three white ones and one brown ones. The grey one make me naar, and I take all my tablets in 30 seconds. Only 30 seconds I take my tablets. They make me naar now. Like I want to vomit now. Because it's...it's sour and not nice they don't taste nice and I'm thinking about it now because I'm talking about it now and I want to naar.'

'Hello my name is Gladwyn and I'm 12 years old and I live in Mitchell's Plain. I get two white ones. 2 white ones and 2.45 yellow ones. The yellow ones make me to vomit. The red ones too. They make me dizzy. I'm not feel nice about my tablets. I believe I'm gonna be better. I have TB-Meningitis. I have meningitis and it's not good. It's TB in your brain.'

Drink or Die

This section focuses on some of the pills which featured heavily in children's explanations of their medicine regimes. It is imperative to understand how efficacious these drugs were, but also, how extreme the side effects could be.⁶⁵ As described by an audiologist at BCH:

'It's sort of like a catch 22 situation right? The drugs can do a number of things in addition to curing the TB. Is it a risk? Yes. Is it worth it to save someone's life? I think so. We just must monitor them, you know? Any sort of alteration in their auditory abilities and the doses must

⁶⁴ In order to insure saliva was not transferred onto microphones

⁶⁵ For a comprehensive overview of TB drug side effects and toxicity:

World Health Organization Report (2005), Stop TB Working Group on DOTS-Plus for MDR-TB, WHO, (2003), Zaleskis (2005), Ecks and Harper (2013).

be changed immediately. It's sad to see kids lose their hearing at such a young age. It's actually tragic.'

Medication was a Janus-faced enterprise. One instance, life-saving, and in another, extremely detrimental to one's health. This was the 'catch 22' the audiologist spoke of; during the assimilation period a child would go through an adjustment phase. Extreme nausea, headaches and a host of side effects accompanied drug ingestion. Children were drilled on the efficacy of their medications and told repeatedly by nurses and the teachers that if they 'did not drink their pills they would die'.

It doesn't feel real. Every day I am surrounded by the kids and they are so healthy acting, but they are so sick. They are told repeatedly by adults that they will die if they do not take their medicines. How can they even fathom death? Their own mortality? (Field notes)



Figure 32: Nkosi's pills, taken by Rosa



Figure 33: Gabi's pills, taken by Gabi, Ward 3

Gabi: ‘So here are my tablets⁶⁶. And I hate them. They make me want to naar (vomit). And then I do vomit. It comes out. These are the big white ones and I hate them Kate.’

The drug pictured is called Pyrazinamide or PZA. It is a mainline TB drug. It causes nausea, vomiting, loss of appetite, mild muscle/joint pain, and abdominal/stomach pain. Patients who take PZA sometimes present with symptoms of liver disease (i.e. persistent nausea/vomiting, unusual tiredness/weakness, yellowing eyes/skin, dark urine).



Figure 34: ‘The big yellow ones’- taken by Gabi, Ward 3

Gabi:

‘I took a picture of these big yellow ones.⁶⁷ They stick to my tongue if I don’t take water. These are too big for me to swallow sometimes. Nurse says to just take them all, like Carlito do. I take mine two by two. And slowly, you see. That’s my way.’ This drug is called Terizidone and it is an MDR drug. It causes neurologic and psychiatric disturbances, including: severe depression, anxiety, panic attacks, psychosis, seeing and hearing things that do not exist, paranoia, dizziness, slurred speech and convulsions. Lesser reactions include nausea, vomiting and skin allergies.

‘I hate the yellow ones. I hate, hate, hate them. Even to think about them now. No man. For me, none is nice. Colour doesn’t matter, they are bitter. Sour-tasting.’-Nkosi

‘I just feel naar all the time. I cannot wait to go home.’-Sierra

Amikacin was a very strong anti-bacterial injection. It could cause serious kidney problems and nerve damage, resulting in permanent hearing loss (including deafness or decreased hearing) and equilibrium (balance) problems. Many of the children had their Amikacin

⁶⁶ See Figure 32

⁶⁷ See Figure 34

injections stopped because their hearing was affected. Rosa, Gift and Themba were three such cases. I was told the first month of Amikacin was the most difficult for children. Injections were given every day of the week in the afternoons from 3:30pm to 4:00pm. Many of the children were afraid of needles, and reviled the burning sensation left in the buttocks area where the injection was administered.

‘Your bum is so sore. You see?’ -Rosa

‘My bum just hurts all of the time, and my ears feel clogged.’ -Marissa

It was common for children to show me their injection sites. Buttocks were inflamed, bruised, scabbed and sometimes continuously bled after an injection. I immediately became conscious of ‘sore bums’ after my first month at BCH, when Gabi reprimanded me after pushing her on the swing. ‘Don’t swing me too hard and don’t touch me there! Gaan man! That’s my injection!’

The ‘Beep box’, X-rays, and ‘the Vampire’

Mary and Opal worked for a local TB organisation collaborating with BCH. Mary facilitated and transported children who were isiXhosa speaking, and Opal facilitated procedures for Afrikaans speaking children. Together, they were responsible for ensuring children participating on the study⁶⁸ were administered monthly blood tests and audiology tests. The audiology tests were also administered to children who were not participating in the study. The audiology department was located across the road from Ward 3 and faced the open space by the visitor’s parking lot. Upon entrance to the audiology room, a sound proof box sat in the corner. This was called the ‘beep box’ by some of the younger patients. Figure 35 shows the beep box.

⁶⁸ The ‘study’ was a clinical trial which was trying to establish better drug dosing for paediatric patients.



Figure 35: Audiology Booth, Audiology Department, BCH

The audiologist closed the door to the room and administered the test. The test comes in a series of low frequency and high frequency beeps in sequence. The child is asked to raise their hand when they can discern the sound. Instructions to the right of the door both inside and outside of the box, are written in the three predominant languages in the Western Cape: isiXhosa, Afrikaans and English. Children generally think the ‘beep box’ is fun, primarily because they think it is ‘like a game’.

‘I like the beep box. It’s like a game sort of. Kind of like a computer from school.’ - Lolly

‘It’s fun because it’s a test, but there’s no right or wrong answers’. - Shelley

‘I don’t really think too much of that thing. At least it’s not blood, or injections.’ - Sierra

‘I get mad when I can’t hear the beeps, but I know I’m supposed to (be able to hear them).’ - Gift

Figure 36 shows the smaller audiometer used for Ward B children. I assisted the audiologist on a few occasions with trying to settle babies and administer the tests simultaneously. ‘Many of our little ones develop inner ear infections. This (test) can be really painful for them, but we have to perform it nonetheless’, she explained as the child screamed and squirmed in my arms.



Figure 36: Audiometer, Audiology Department, BCH

It astounded me how routinised these types of tests became for paediatric patients. They walked from the audiology department to the x-ray department on nurses' orders. There was a certain sense of freedom, excitement and adventure that the BCH grounds offered a child: being able to negotiate the facility largely without supervision. The x-ray department sat behind Ward 3. X-rays were never feared, and children thought some technicians in particular were very nice. One day after an X-ray session, I asked some of the children the purpose behind taking x-rays.

Rosa: 'X-rays are pictures of your lungs mostly. But things come up in there.'

K: 'What do you mean, what type of things?'

R: 'Well *mos*', like you can see everything. Like if you have a closed up pipe or a shunt – sometimes you can see those pipes in the neck. Also you must look for white stuff. The TB look white, nuh? White *dingus* is bad.'

K: 'Ok, what are some of the other colours you see?'

Nkosi responded, 'Well the whole back (background) is black, and the bones are white on there. I think TB looks like whitish grey-like spider webs in your lungs. Hanging and stuff, you know?'

Lastly, and probably the more painful routine children endured, were monthly blood tests. Blood tests were administered through taking multiple vials of blood while the child sat in a chair. This blood was tested to establish the liver function and the levels of medication in the blood. Ward 3 children called this 'the Vampire'.

Nkosi explained, 'Yoh. It hurts Kate. Like really! And if they can't find the thing in your arm...some nurses are good and some are bad.'

K: ‘What do you mean – the vein in your arm?’

N: Yeah yeah yeah, the vein. This one nurse, she was just jabbing me again and again. She couldn’t find it. It felt like stabbing. And you can’t move.’

Sierra explained:

‘You go into that other ward, and sometimes it’s during school, which is fine. But really I would not like to go there. Keep me in school. Don’t take me for bloods. It hurts and it makes a mark on my arm after. Sometimes it bruises...yoh. Eina!’

Rosa wanted to hurt the nurse because she did not ‘do it right’. ‘I was going to *moer*⁶⁹ her. Eina⁷⁰! That stupid woman – I didn’t know that one. I think she’s not working here much.’ I asked her if she knew most BCH staff. She responded, ‘Me? I know *everyone*. And you better know *mos*, you jab me with the vampire to take my blood, it must be done so (she demonstrates with a pen on my arm). You see? Soft-like. Not like so.’ At this point she took the same pen and stabbed the table top.

For Gabi, the Vampire made her angry:

‘I’m going to tell you, it makes me angry. They make you just sit, like so. You can’t go nowhere. You sit and sit and then you have to have the whole cast thing put on, and they make so...and that little plug they do put it in your arm. Next time I see my mummy, I will tell her to make them stop. She can get really mad. So that will help me for them to stop the Vampire. My mummy can do anything. She love me. But it makes me angry, so angry! Also, it hurts, which makes me sad and angry. I do cry a lot too.’



Figure 37: Gabi’s arm-‘The Vampire’, Ward 3

⁶⁹ Beat up, physically assault

⁷⁰ Ouch!

This chapter related how children's bodies and lives were inscribed and choreographed by biomedical procedures. Children were acutely aware of the spaces, tasks and regimes they negotiated as well as the TB inside their bodies. Different rituals, like pill-drinking, became normalised and helped configure the child as a 'responsible' paediatric patient at BCH (Robbins 2006). Agency here is an unhelpful concept given the amount of surveillance Nurse Lily described. Despite the amount of protocol (Human 2012) and extra protocol (Dixon 2012) employed by nurses and doctors, Livingston's notion of improvisation (2012) is the most helpful in assessing the social, political and economic structural challenges in each child's life. The child's body bore the imprint of structural disjuncture that came into view within Ward 3. Rendering a child a paediatric patient was a way to pragmatically and efficiently assist in the rehabilitation of their well-being and health at BCH.

The following chapter gestures towards another figuration, that of the 'student patient' at the BCH School where children attended class daily. The school offered a distinctly different space to that of Ward 3 or anywhere else in the hospital. Here, teachers Theresa, Grace and Candice experienced bureaucratic hardships at an institutional and structural level while grappling with their students scholastic, social and physical difficulties. Teachers spoke to the challenges unique to working in a hospital school, and the ways in which they tried to equip student patients with the tools they may potentially require in the future, outside of the classroom, after treatment.

Pedagogy on the Fringe: The Intersection of Education and Hospitalisation

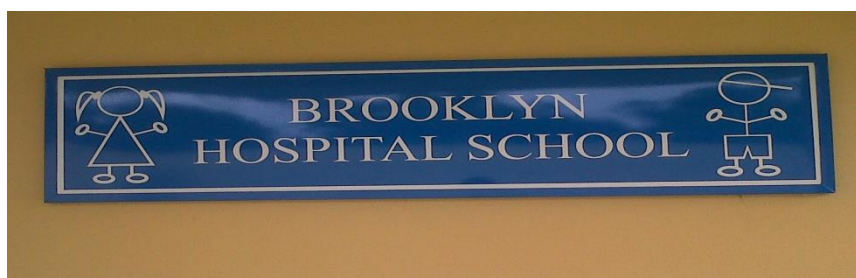


Figure 38: School sign, Brooklyn School

‘This is not a school, this is a hospital. I learned that early on Kate. Yes, the children are taught here, we try to continue their schooling, but their health is first priority. They don’t feel well? They sleep. They need to vomit? Go for blood? Get an x-ray? Get any sort of test or see the social worker? They must go and do that.’ – Teacher Theresa

The Brooklyn School (see Figure 38) was an educational facility enveloped within a healing institution, also commonly referred to as a ‘hospital school’. This is where education and Western biomedicine collided, and tried to work alongside each other, for the well-being of the child-patient. Theresa frequently employed the above explanation, and I was struck by her statement. For her there was a discrete difference between the services offered by the school and hospital, although they operated within the same institution. The school, according to most of the children, was the most important place in their daily life. ‘I don’t know what I would do if I didn’t have school’, or ‘it’s the best place here at Brooklyn’ were sentiments heard often. I thought of Brooklyn School as both school *and* hospital; a place where children were healing *and* learning. The school functioned as a fundamental part of the healing process at BCH. Conceptually speaking, schools and hospitals serve similar functions. They both institutionally facilitate the provision of inalienable human rights: human rights in the form of access to healthcare, and the provision of a basic education. Both of these processes – healing on the one hand, and learning on the other – are similar in that they are both dependent on, and unified by, growth.

Chapter 3 focused on the rules and regulations that were established to configure the child as patient. Many of the rules eased the work schedules and constraints of the nurses, but not necessarily the children who lived there. It became apparent throughout my research that children did not consider the ward to be a place of comfort. This perhaps is not surprising given the routinised procedures which occurred there. In contrast to the ward, Brooklyn School was

a place of safety and comfort for the children. Here, children are configured as patients receiving care and students learning about care. Children received a non-traditional education in care, rather than an overt scholarly education. Lessons in care foregrounded, and sometimes were interwoven into academic lessons. Teachers considered ‘Care’ necessary for each other and for their individual growth, healing and overall well-being.

This chapter first traces the concept and history of hospital schools and the correlation with many of the challenges and ambiguities within the BCH context. Conversations with teachers provided insights on how children assimilated to fulfilling multiple roles in exceptional circumstances: that of both patient, and student at BCH. The data revealed that this ‘non-traditional’ education and learning environment was anything but rigid, and experiences instilled in children had far less to do with academics than with lessons around care. Rather than expound upon pedagogical styles or models, this chapter brings together the experiences of those teaching on the periphery of government provisioned education in Cape Town.

In Chapter 3, doctors and nurses lent their voices to the figuration of the child as a biomedical object, the TB bacteria inhabiting their bodies, and the compliance necessary to facilitate healing. There was a strong sense that however ill the child was, there was a conscious effort on behalf of physicians to treat ‘the whole child’. Doctors recognised that beyond the physical body or the boundedness of the bacteria walls, was a person, with a context, and although not always, a family and a home to eventually return to. This idealised healing collaboration is by no means commonplace. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* (Fadiman 1997) chronicles the ruptures in the life of a young epileptic patient through the discomfort between American and Hmong cultures, cross-cultural medicine and discordant communication. Readers are led to believe that Lia Lee’s life is ruined by the combination of all of these things: irreconcilable differences rendering tragic consequence. Anne Fadiman’s work made the argument for greater cultural competence between medical practitioners, their patients and the challenges they may encounter during the diagnostic and treatment process. Fadiman suggests that ‘conjoint treatment’ or ‘a concern for the psychosocial and cultural facets that give illness context and meaning’ is absolutely vital to the patient-practitioner relationship, given the deep-seated effects of chronic illness on a child’s life (and that of their family) (1997:265). She adds:

‘I have always felt that the action most worth watching is not at the center of things but where edges meet. I like shorelines, weather fronts, and international

borders. There are interesting frictions and incongruities in these places, and often, if you stand at the point of tangency, you can see both sides better than if you were in the middle of either one.’ – Anne Fadiman (1997: viii)

Fadiman’s theoretical reflections compel the reader to consider a place of ebb and flow: of uncertainty, inconsistency, and ultimately instability. The metaphorical shoreline she depicts could just as easily describe the uneasy marriage of education and medicine at BCH. The coming together and the falling apart of the sand on the shoreline and the water lapping it, makes it difficult to distinguish which is coming, which is going, which is stable or mobile. The two coalesce and return, only to collide once more. This imagery best describes that which I fail to adequately articulate with words: the hesitations I had with calling the school *just* a school, or resigning myself to Theresa’s description of the school as a *hospital*. Therefore Brooklyn School was both, but at different times; for me it was pedagogy on the fringe, a hospital school.

The Hospital School

Existing literature maintains that children with chronic illnesses are at risk academically and psychosocially when hospitalised for long periods of time. Understandably, their daily routines (including school attendance) were interrupted when hospitalisation was deemed necessary. Equally, illness was ever-present in the school-lives of chronically ill children: from the anxiety of being ill, to absenteeism, to relationships with peers and the support of teachers, chronic illness has a dramatic impact on the experience of education (Sexson and Madan-Swain 1995, Boekearts & Röder 1999, Shiu, 2001, Oberstein 2012). As mentioned in Chapter 3, TB and pharmaceuticals produce specific side-effects which may inhibit learning, including: fatigue, impaired attention span, and issues with memory (Thies 1999).

Schlozman suggested that school was a ‘luxury that quickly departs when a child falls dangerously ill. In this sense, school becomes a refuge, and educators should understand their crucial role in protecting this *sanctuary*’ (2002:83, emphasis mine). Ward Three children’s experiences substantiate this observation, as attending school signalled a return (however minimal) to a normalised routine. Breitweiser and Lubker distinguished hospital schools from traditional schools ‘in that they often have membership in two of the most powerful service systems in our society: the health care system and the education system’ (ibid: 27). They suggested that ‘hospital schools provide academic programs for children both to promote

normalizing activities in an abnormal environment and to minimize interruption of studies when children are hospitalized' (ibid: 31).

I was unable to find significant historical literature of hospital schools generally, much less in the context of South Africa or Africa. Similar to historical accounts of TB as related in the introduction, studies focused primarily on North America. In addition, many of the histories provided focus purely on the development of schools for the visually-impaired or speech-impaired. For example, Perkins⁷¹ - founded in Watertown, Massachusetts in 1829 – is the oldest school for the blind in the United States. Their work extends now to 67 countries and they serve over half a million people world-wide with their educational products engineered for visually-impaired people and their families.⁷² Helen Keller was the most well-known, iconic student who attended Perkins, but had a tumultuous relationship with the school.⁷³ Nevertheless, the institute has been instrumental in providing learning tools, products and a world-class education to those who are visually or speech-impaired.

In other literature, Rankin's (1993) work focused on the development of hospital education programmes in the United States: primarily in Chicago, Illinois. This Midwestern city was a forerunner in early hospital school programmes and serves as an illustrative example. As early as 1893, Chicago recognised the need to continue the education of children who resided in a facility called 'The Home for Destitute Cripple Children'. Each morning the children were required to attend academic lessons provided by the home. This in order to 'help on a healthy, purposeful growth, thus preventing as far as possible the disease of mind and character which seems sometimes to be the natural outgrowth of a diseased body' (Rankin 1993:8). Rankin specifically focused on the chronology in Chicago: the provision of hospital-based education programmes and the legal and legislative splintering out into 'special education' services for hospitalised children. Nonetheless, recent scholarship demonstrates that continuing one's education while chronically ill, or being able to attend school during a long term hospitalisation, is a priority for paediatric patients (Wolfe 1985, Rynard et al. 1998, Shute 1999, Bessel 2001, Nisselle et al 2012). Other research illustrates that a prolonged absence from school causes anxieties and concerns both for the maintenance of social relationships and 'keeping up' with schoolwork (Sullivan et al 2001). Shiu (2005) and Shute and Walsh (2005)

⁷¹ Formerly known as Perkins Institute for the Blind

⁷² See: www.perkins.org for more information

⁷³ See McGinnity et al (2004)

found that student support from educators and the educational institution wanes after prolonged school absences.

Pedagogical theory-driven studies focused on the content of learning modules at hospital schools. Nisselle et al (2012) conducted research with laptop accessibility and provision with an Australian paediatric hospital. They found that the benefit of laptop accessibility helped to foster ‘a learning culture at the hospital through their capacity to facilitate impromptu, informal, student led learning’ (Niselle et al 2012:16). The use of educational games (Gee 2003) was also integral to this ‘learning culture’.

Oberstein’s (2012) recent insights demonstrate the positive influence of hospital-based education programmes in a paediatric hospital in the United States, however she focused on the educational content and provided recommendations for improving the programmes in place. Given the social, political and economic dimension of the scale of comparison, her study, while valuable, is incomparable to the South African environment where the education system (much less that of hospital schools) is in a state of uneasy flux.⁷⁴ If the state of education in South Africa is already teetering on the edge of accountability and credibility, what can be said for an alternative, yet supplementary school like Brooklyn hospital school? Within the South African context, Van Heerden explored the implications and barriers of grouping special needs children with those who were chronically ill within the same classroom at St. Joseph’s Home in Cape Town (2009). This is the only South African work that grappled with the provision of education within a non-traditional academic environment and simultaneously tried to address education provision for chronically ill children. While it is acknowledged that these two groups or categories are lumped together often, it is beyond the scope of this chapter to discuss the varying interpretations of the ‘special needs’ category or to examine Education Policy in South Africa.⁷⁵

The following section introduces the school routine. Like the ward, the Brooklyn School (see Figure 39 and Figure 41) was temporally contingent on a set schedule. I provide a brief history

⁷⁴ South Africa’s issues in basic education provision and the on-going ‘textbook scandals’ are well documented. See Nkosi (2013) and John (2013) for more information.

⁷⁵ For more information see: Department of Education (2001). Education White Paper 6: Special Needs Education. Pretoria

of the schools existence according to Theresa and Grace in addition to the Ward 3 nurses, Nurse Jones and Lily.



Figure 39: From the gates of Brooklyn school

A Daily Routine

Every morning after drinking pills, eating breakfast, and brushing teeth, we walked across the property in a winding procession to the school. The smaller children from Ward B joined, and the walk continued to the main gates of the school. Metal fencing enclosed the lemon cream school house on all sides. The front gates remain latched to prevent adult patients and visitors from wandering onto the school grounds. There was a playground with a set of swings and monkey bars outside in the yard (see Figure 40), in addition to toys donated by different organisations and individuals.



Figure 40: Brooklyn School playground

The Brooklyn School contained two classrooms. The front classroom housed 12 desks which all faced the main white board, away from the front set of windows (see Figure 42). Similar to the ward infrastructure in chapter 3, extraction fans hung from the ceiling accompanied by UV lights and open windows to circulate air. Down the small corridor there was another room which served as the library. At the end of the corridor, a back gate opened up onto a small courtyard. Candice's classroom sat off this area. Within the main building there was also a computer room with brand new computers for the children to use, in addition to a small kitchen and boys and girls toilets.



Figure 41: Front stoep, Brooklyn School



Figure 42: Main classroom, Brooklyn School

Upon entrance to school, children formed a line to greet their teachers and enter their designated classrooms. Theresa stood at the front of the room and greeted children in English, Afrikaans and isiXhosa. Children completed the work assigned by Theresa at a personal wooden desk. I worked primarily with Theresa's classroom, but on occasion, Candice asked

me for assistance. The children attended school from 9:00 am to 10:30 am and then had recess on the playground (see Figure 43) until 11:30am, at which time they had lunch in the ward. They returned at 12:30pm for an additional hour and a half of school activities. On Wednesdays, the school visited the local Brooklyn library for craft activities or story time (see Figure 44). Mark, a volunteer, visited on Tuesday afternoons when he and the children made crafts. Fridays were reserved for watching movies.



Figure 43: Swinging during recess, Brooklyn School

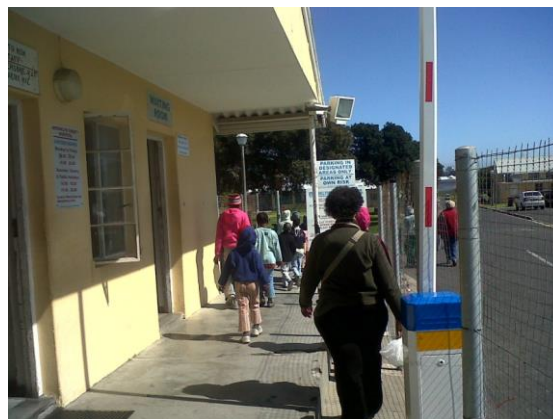


Figure 44: A trip back from the library, BCH

During the time of research, there were three teachers employed at the school. Theresa was the headmistress for the past five years. At 58 years of age, Theresa had over 40 years of experience teaching in government (public) schools in South Africa. At school she taught Grade 4 to Grade 12. Three months into my fieldwork, Teacher Candice, also 58, began working with Grade R to grade 3. Teacher Grace was 38 and taught the Grade 0 children,

operating primarily from a small classroom in Ward B. Both Theresa and Candice were Afrikaans-speaking and Grace spoke isiXhosa. All teachers were fluent in English. Given the linguistic makeup of the students, multi-lingual proficiency was an absolute necessity, especially if the children in the hospital at the time were not able to understand all three languages. Throughout the research, older children easily negotiated all three languages and assisted in translation when necessary.

‘One small room’

Brooklyn School was born out of the need for a formal schooling environment alongside long term inpatient care. Leading up to its ‘formal’ establishment in 2011, most of these schemes resulted in failure. According to Nurses Lily and Jones, the school had been in existence for over twenty years. Given the increasing influx of child patients, in addition to the length of standard treatment, the hospital administration – made up of the hospital superintendent and the South African Medical Education heads – felt that schooling was a vital component for children of school-going ages. Previously, nurses working in Ward 3 taught *in addition* to their daily duties. They struggled trying to assess which work was age-appropriate for certain children. ‘Yoh, it was crazy back then, *mos*. I wasn’t taught how to teach. I am a *nurse*, I went to school for that, not teaching’, explained Nurse Lily.

Nurse Jones reflected on the ‘early days’:

‘Those were different times back then. The children were *so* sick. Kate, you wouldn’t even believe it. Walking skeletons, I tell you. And they were much better behaved. They were quiet. Some came in and you’d think to yourself, “This one isn’t going to walk out of here”. But they did, eventually.’

In addition to the nursing staff, there were volunteer teachers. The stoep of Ward B was the makeshift teaching space, and Tygerburg hospital donated all teaching materials. Another proposal was to transport occupational therapists and teachers to Brooklyn to facilitate their sessions with child patients for one hour a day. According to Theresa, this idea never materialised, because like the previous solutions, it was neither sustainable, nor practical. In the meantime, Tygerburg Hospital fought hard for the registration and formal establishment of the school. Eventually, the school was moved to the new (and current) site, despite the (education) department’s attempts to close it for over ten years.

When Theresa spoke of registration, she reflected on her tenure at BCH. Theresa came to the school five years ago in 2008. At that time, the school was housed in the building which was later converted into the hospital tuk shop. She explained, 'It was everyone under one roof. I taught all grades in one small room.' In 2011, construction commenced on an out building that was used as an additional, but smaller, nurses' residence. As Theresa explained, 'A woman and her children were staying here, and a few other nurses. They weren't happy to leave. I was told they turned on all of the water taps when they left. Yoh, the place was destroyed when they (the builders) came in.'

In 2011, The South African Medical Education (SAME) Foundation provided funding for renovations and refurbishments to the school, marking its formalisation. Theresa described to me how, during the opening of the school, the 'big wigs and so-and-so's' came and 'took pictures' and left. Since the original commemoration, she had not seen the department of education heads. 'And still, we're not registered Kate, it's just one ongoing, up-hill battle.'

The Brooklyn School was classified as one of seven 'hospital schools' in the Western Cape, joining schools in Tygerburg Hospital and Red Cross Children's Hospital. Brooklyn School was not registered with the Department of Education, nor was it an independent school. It was an 'affiliate' or sister school to Mulenbeeck: a school for children with 'special needs'. The headmaster of Mulenbeeck administered the school, but it was Theresa and her team of teachers who facilitated the teaching and day-to-day administration thereof. Towards the completion of research, Brooklyn School remained unregistered but was not entirely independent, and therefore it perpetually occupied an ambiguous space.

The following interview with Teacher Grace revealed the bureaucracy and challenges the teachers experienced without formal registration. Many of the thick bureaucratic processes mentioned in Chapter 3 appear here, but in relation to the school itself. Grace explained:

'It doesn't make sense that the school isn't actually registered...but it isn't. It's shocking. As *not* registered as it is, it's still a school. We teach them what they are supposed to be taught at the schools outside and we try by all means to come in terms that this is a school in the hospital. So again, that flexibility needs to be there. There are doctors that need to see them, there are psychologists, there are the OTs (occupational therapists), the ear (audiologist) people, the social workers, when they need to draw blood...it's all of that stuff. We can't actually be that rigid with all these things going on. We obviously can't be as strict as the school on the outside. We try by all means for them to get a better education – a good education and when they go outside at least they are not left behind.'

‘...The assimilation to the home school is also very problematic. There are some issues. Because most of the time, when we get a new child we try to work with their ‘old’ school if I can call it that...the outside school. And that really doesn’t work well. We don’t get work from those schools – the curriculum, course work, we ask them out there to give us work so we can continue with their education through a syllabus and other materials. They don’t cooperate. We call them, they promise and they don’t do. They don’t deliver. Sometimes they don’t answer repeated phone calls, or the phone has been disconnected at the school...or they don’t even have a phone. How is that possible? The major issue is this.’

When a new patient arrived, they carried a sticker from Ward B. These stickers were labels which contained vital patient information, such as: full name, age, sex, admission date, patient file number and contact details. The stickers classified every personal item a child possessed at the hospital, from medicine, x-ray films to individual drinking yoghurt. It was a mode of institutional identification of patients.

Theresa welcomed new students and asked them to name their (old) school, and where they were ‘from’. Based on this small conversation she would assess the child’s linguistic preference as not all children were competent in all three languages. Later, she referred to a folder containing the entire listing of schools in the Western Cape. This was usually the first stumbling block. If the child did not know how to spell the school name, or it could not be found in the listing, further contact with a guardian was necessary. Sometimes, the school was not listed. Many school administrators failed to return phone calls or the school phone lines were inoperable (or did not exist). A school representative promised to return the phone call or message and failed to follow up entirely. This process was exhausting and arduous for the teaching staff. ‘They just don’t understand how important this is...to try to provide consistency’, explained Theresa. ‘This is their future, and they don’t seem to care. Some do, but definitely not all.’

Daunted at the task of preparing perhaps thirty individual syllabi, I asked Grace, ‘So you are all trying to assemble different syllabi just like that?’

‘Just like that, yes. All the way up to Grade 12. And I have also spoken to my classmates from my early childcare development (ECD) course out there (she points away) because most of them are working in the crèches. They have a syllabus and a curriculum. I ask them for ideas, for themes, and they help me out. So most of the time they are the ones that help me. I have to know what is happening out there, and so I ask Please guys... I don’t know what is happening out there in the world.’

Grace's spatial references framed the school as a place apart, separate from the *real* world, whereas Brooklyn in its isolation signified a different spatial identity altogether. Marshak's research in Swaziland around adoption also echoed these spatial elements (2013). To borrow a metaphor from her work (ibid), the school, the hospital are somewhere on the fringe of an island, in the middle of a large expanse of water, with very little contact with anything else, be it the outside world, or 'the mainland'. Marshak made the distinction between the 'island' and the mainland, demonstrating the politics of place and the spatial narratives her collaborators attached to their organisation and the town of Bulembu (ibid: 26). It was on this 'little island within an island' that bureaucracy was made more tenuous via the unregistered status of the school.

Grace continued:

'Yes, it is...because if we were registered, we would have all of this information from outside. They would deliver the textbooks and the coursework no matter the number of children or their grade. You have some patients who are here for years, we had two patients who you may remember who were here for three years a piece...and they are in an unregistered school all the while. We do all we can to make the situation work, but it's totally hectic.'

Grace's sentiments echo the technologies of invisibility Biehl (2005) spoke of in Chapter 3, as well as the thick bureaucracies of the Department of Education. These often tedious particularities could have significant impact on an individual learner and their school future.

Towards the end of my research Theresa seemed preoccupied with the 'drop in numbers' (of children). She explained:

'The children now, there are less of them...they are younger. We don't have *so* many, you see. I look at my (classroom) numbers. They're going down. I don't know if its Prof's new medicines, are they using them yet, do you know? Or people are more knowledgeable and take their kids to the clinic sooner, or what. I'm happy that children are getting well more quickly, but what will I do if there are no children? We have to have children to keep the school going.'

Beneath her veiled sentiments, she expressed concern for her own well-being and professional future at BCH. 'I have seven more years to teach (before retirement), and I want them to be here', she explained. Her questions surrounding Prof's 'new medicines' conveyed a disconnect between life in the Wards, ongoing research projects and the ways in which this information was fed back to the school. I speak to these other disconnects and punctuated lapses in communication between the wards and the school later in this chapter.

‘How long will I stay?’

Theresa consistently reminded the children to stay active, whilst simultaneously reinforcing how unique each child’s condition was. As discussed in the introduction, not every child would have the same length of stay, nor the same treatment regime. Some children became upset when they saw another child get discharged earlier than their estimated discharge date. Children involved in Prof’s study were subjected to additional procedures. Phelo explained, ‘I don’t think it’s fair that I have to take blood and she doesn’t. It’s not fair...and it hurts so much Kate’. There was very little recourse one could take, but Theresa managed to put every individual circumstance into perspective:

‘We’re not all the same. Maybe some of you have the same TB – but our bodies work in different ways. Sometimes one of you may have a headache and you take one grandpa (aspirin) for it. But if another has a worse headache, he may have to take 10 grandpas.’

Theresa attempted to sensitise the differences in discharge dates, whilst simultaneously alluding to the problematic biomedical assumption that bodies everywhere are the same (Lock & Nguyen 2010). Oftentimes an individual child’s situation relied on tenuous social circumstances, and Doctor Early refused to release a child to abusive, alcoholic or drug dependent families or guardians.⁷⁶ As discussed in the introduction and chapter 3, individual bodies responded differently to TB medication.

Often, new patients appeared sluggish because they were adjusting to the pills, whilst simultaneously making the mental and emotional adjustments to life in Ward Three. New patients slept often: at their desks with their heads down, or on the floor with a blanket and pillow. Again, the physiological responses to side effects in this setting, paired with the demands of academics, cannot be underestimated (Thies 1999). Theresa encouraged children to be as physically active as possible through her employment of metaphor. When Theresa spoke about TB metaphorically, the biochemical processes became more accessible, more familiar, and more personal for individual children. TB in this instance was relatable, it could be discussed. This type of translation was imperative for children to better understand what was happening to their bodies and differed dramatically from the ‘doctor speak’ (and biomedical renderings of the paediatric patient) featured in chapter 3.

⁷⁶ In these types of circumstances, there are legal ramifications in place to protect the child’s well-being. Doctors, social workers and nurses are bound to adherence of legal statutes.

‘You keep the TB nice and warm and he tells you to be calm and stay still. And if you start running and jumping it will come out zooooop! And he’s gone. You make the TB germ happy when you cover up. Germs don’t like fresh air, so we’re gonna get a lot of it! You must play and run and jump and go go go! You must play in the sun, but don’t sit so...with a thick cap and a jacket like that...feeling sorry for yourself – oh woe is me...get over yourself! No man, don’t be sad. TB likes to be bundled up – to stay warm and to make you inactive. You must be out in the sunshine playing and enjoying yourself! Is your germ happy inside of you? Yes it is! You must be happy too, but let’s get rid of the germs!’

Her animated explanation evoked laughter every time she initiated the monologue. She provided different variations of the explanation, however, every speech included one part history, epidemiology, metaphor and basic health education. Her explanation and subsequent persuasion to be active contrasted sharply with the sanatoria ethos of 18th and 19th Century Europe or North America as presented in the introduction.

‘We never want to see you again’

There was a long waiting list to be admitted into BCH. Like many parts of Africa and the developing world, need outstripped supply.⁷⁷ Children waited in Groote Schuur, Tygerburg and Red Cross Children’s Hospital. There was a ‘push’ to release patients who came from stable backgrounds in order to ‘open up’ beds for children in need of BCH’s services. When patients departed, there was a ceremony at the school. We stood in a circle and recited the following chant for one such discharge, Khadija, who had previously defaulted on her pills only to come back to BCH for a second time. She had lost her mother to AIDS-related complications, and was being raised by her aunty.

‘Good bye Khadija. We will miss you. We all love you. Take your pills. Go to school. Listen to your mother and be good. We never want to see you again!’ we recited. Saying goodbye was difficult: replete with nervous smiles, a lot of tears but many hugs. One by one, we went around the circle and said our goodbyes. For Khadija, Theresa explained she mustn’t come back to BCH again. She would be on pillis for the rest of her life, and Theresa implored her to continue her treatment. On no occasion was it mentioned that Khadija was HIV positive, but she knew that she had to drink the extra pills.

⁷⁷ Livingston (2012) too references this in Botswana

Theresa gave departing patients school supplies and their academic work to show to their outside teachers. She explained as she stuffed supplies into a packet, 'It provides a little relief to the family, you know? They can try to get back to normal and not worry about school supplies.' She also provided each patient with a personal letter addressed to their headmaster. The letter explained that all requirements have been met and to admit the patient back into school. I walked Khadija backed to the ward to say goodbye. I reminded her to take her pills.

She replied:

'I know Kate. I'm 14! I know what to do now. I stopped because I was sick and tired of them pillis. The pills were my life. You had to take them every day. I didn't want to. I'd rather die. But now, I want to live. I promise you *mos*, I'll take them. Even the *other* ones (ARVs). I have more time still for the TB pills, but I'll take them.'

We walked to the ward and met with her aunt. Nurses Jones and Lily packed up bags of TB medications and ARVs. 'You be good nuh? Mind your aunty. Take your pills and go to church!' commanded Nurse Jones with a smile. And then, Khadija was gone. I never grew accustomed to the revolving door of patient discharge and admittance of patients, but the ceremonies instructed by Theresa, Grace and Candice helped to forge a bridge back to the outside world for the children on their departure.

Grace

Although Grace was the youngest of the three teachers, she had taught at BCH for the longest period of time, while simultaneously raising four children and going to college part time to get her ECD (early childhood development) certification. She had experience in trauma counselling and emotional support. She was not technically employed by BCH, but worked instead for a TB non-governmental organisation (NGO) operating in Cape Town.

She explained:

'I started here at BCH in 2006...I started as an 'educare' teacher in Ward B and I worked there for three years until they employed other teachers. I moved to the school. When I came here – there was a teacher I don't remember her name – but she preferred to work alone. And there came a need where they needed a Xhosa speaker to translate – she was Afrikaans – and we had a lot of Xhosa kids. I was moved to the big school. I worked with her until I translated and I worked teaching grade R, 1, and 2, those three grades. I worked well with her. Things went smoothly she actually taught me a lot of things and I gained a lot of experience from her. She really was a good teacher to me too. So then I moved back to Ward B because of some politics and I worked in Ward B and when I worked in Ward B there was a need again for me to go

back to the big school. So I'm kind of a ball whereby they kick me around. If there's a need this side you go this side if there's a need on the other side I go that side. And I just decided to be flexible you know? Wherever they kick me to I just go with the flow. So currently, I am a grade 0 teacher. My children are in Ward B. I come to collect them every morning actually from 9 am I do the morning music and everything and then I take my children to the school. That is when I start with my activities at the school with my grade 0s...Grade 0 is 3 to 4 years old. I have 9 kids at the moment...there are 6 Xhosa and three coloureds.'

As a single mother, she earned a minimal income, she sent her two eldest children to the Eastern Cape to attend secondary school and stay with her mother. 'I just pray Kate. The big guy up there? He always guides me in the right direction.'

Candice taught the children from grade one to five. She came from Mulenbeek, the sister school, and my research coincided with her first year of teaching at the Brooklyn School. Theresa initially requested a high school teacher from the Department of Education, not a primary school teacher. She admitted that she 'gave Candice a hard time for the first month', but later agreed that she needed someone to 'help share the load' of teaching.

Coming Back from the 'Outside'

If a child had a stable home environment, they were allowed to visit every other weekend as discussed in the introduction and chapter 3. Upon arrival back at BCH, some children had stomach issues, vomited when they took their meds or were exhausted. 'They go home and they eat crap. Greasy meat, or too much meat...*spookies*⁷⁸ and just junk food. Parents think they are spoiling their kids, but it's making it hard for the pills to take hold', Theresa explained. Another issue was pocket money. More 'fortunate' children returned with money provided by their caregivers. This money could be spent on Fridays at the tuck shop. The BCH tuck shop offered food the children were not encouraged to eat, and was more similar to the food they would eat outside of the ward. 'I don't know why your parents are giving you such an awful amount of money...Your parents can buy things for you on the outside and bring it in, what do you need all of this money for?', Theresa remarked.

The first conversation every Monday morning revolved around the weekend. I spent weekends in the ward, where we played games, watched videos or sat in the shade, eating *bompies*⁷⁹

⁷⁸ Popped corn snacks

⁷⁹ Frozen fruit juice popsicles

when the weather was too hot to play. Often the children complained of being bored without school to attend on weekends.

‘It’s just not fun when we don’t have school.’ - Rosa

‘I like school because of teacher. She make it fun for me. Not like the ward. It’s so boring there’ - Gabi

‘At least we can play that side (at the school). Here (in the ward)? Yoh. It’s terrible man.’ - Nkosi

Loneliness and boredom were especially common during holidays. Sometimes caregivers never showed up to fetch their child, and I was not present every weekend. Children constantly expressed how they missed the teachers and the playground over the weekends and during holidays.

‘I love the teachers’, Marissa explained. They’re better than my teachers at home. Those ones are so mean.’

And yet, sometimes children did not return to Brooklyn timeously. One such situation involved Carlito, who went missing for over a week and a half. Dr. Early and Victoria, the BCH social worker, went ‘out’ to find him.

Carlito came back today after an extended visit home. His hair was cut and he has scabies all over his arms, little puss-filled bites...he is constantly scratching. The nurses also think he has flea bites...but they explained it was from lack of hygiene – that the linens probably hadn’t been washed in some time because he also came back unwashed. The nurses are convinced his mother isn’t fit to take care of him. (Field notes)

When Carlito returned he was very quiet. I asked him about his home visit and he said nothing. When the children ate snacks that morning, he asked for a second helping of potato crisps. Theresa speculated that he had not had breakfast yet. Candice was Carlito’s teacher and had grown attached to him. ‘That mother doesn’t even know what she’s doing. She has such a beautiful boy and she’s just messing things all up!’ she lamented. ‘Have you seen her before? The situation sounds terrible.’

I had seen Carlito’s mother and stepfather before, because I spent time at the hospital during the weekend. Carlito’s mother only visited once after his admission in December. It was a Saturday in late March, and we had just finished watching a movie. When they arrived in the

ward, I greeted them and Carlito came to my side. Carlito stood there and looked up at me and gave me a toothy smirk. He tugged on my hand a bit, squeezing it sporadically. ‘Buddy - it’s your mum’, I said. I nudged him forward, but he did not move. One hand firmly gripped mine and the other placed in his mouth as he was prone to do when he felt anxious.

I looked back down at Carlito. I crouched down. ‘I’m going to go now and draw. Have some time with your mother, nuh?’ ‘She’s not my mother. You are’, he said. ‘Buddy, look, she’s here for you. To see you’. Carlito wasn’t moving. I nudged him in the direction of his mother and he eventually relented, but asked me to stay in the room. I helped him with two big chairs and they sat, silent, over a litre of cool drink (soda) and spookies.

Carlito’s mother was allowed to visit, but he was not allowed in her custody. Dr. Early and Victoria kept a close eye on the situation. Dr. Early explained:

‘With Carlito, I had sat down with his mother a couple of times and clearly explained what I expected of her. Like going to the clinic and getting treatment for herself. I usually wrote it down as "her homework" before she can have her child for a weekend. I usually contact the local clinic as well and the social worker contacts the outside social worker to do a home visit and assist mom in decision making regarding her own living conditions, choices and personal empowerment.’

Candice was especially fond of Carlito. She explained to me how she was assimilating to the social circumstances many of the children have to cope with at BCH.

‘When I was growing up, there was only black and white. There was no grey... My father was like that...He was a very strict man. This was this, and that was that. But this place...the things that happen. You’re faced with grey situations...So I’m learning how to deal with it...with the ambiguities and how to deal with them. I mean – what must you do? Tell the child their parents don’t want them? Tell them their parents have a tik addiction or drink too much? How? So I tell a white lie. I sugar coat what I say to spare them the truth. There is time for the truth later in their life. If they don’t know now, they can know later.’ - Candice

Carlito’s mother visited him at BCH once more, and it was to be her final visit. This is discussed in more detail in Chapter 6.

‘This is our everyday...this is our normal’

The following interview with Grace demonstrates some of the challenges she faced as a teacher in trying circumstances and how a hospital school is a completely unique environment to work in.

I asked her about the challenges teachers encountered when a child was admitted to BCH. I explained how I often heard in the patient reviews that there were ‘average’ or ‘normal’ social issues.

‘You don’t see white children here...I think for some people that’s a revelation, but it’s normal for us here. I’ve never seen a white patient here. The majority of the children who are here come from very dire situations and circumstances...This is our everyday...this is our normal...for other people it’s hidden. It’s so hard to see parents that have a series of issues and the situation seems impossible. Yoh! Some of these people – the parents – when or if they do visit their children...or that one time I see them when they visit...I feel like killing them. The parents.’

Statements about the moral character of parents or caregivers were not isolated to Grace’s opinion. Many of the BCH staff moralised parents based on the attention they provided or deprived their children of while they lived at BCH.

‘Of course you want the children to be fine. You want them to be healthy and to be discharged. But when you get close to them? It becomes so sad. It’s like you are losing them, it’s like they are being pulled out of you. You are losing a piece of yourself...especially when it’s a situation like that one...so yeah...there are other children that lose their parents while they are here...this is especially hard. And doctor will just call me and say Grace, so-and-so’s mother passed can you tell the child. It’s not just telling that child. You must go a long way with that child. Grieving and all of that. It’s hard to do that sometimes.’

The conversation shifted to Themba, whose mother passed away before the Easter holiday. She was a patient at BCH but ran away with her boyfriend at the time. There were scant details about his father. The outlook was grim according to the nursing staff. I asked Grace if she had counselled him too.

‘I walked a long way with him yes. He wasn’t actually aware of what was going on. He kept telling me that mother came today or I saw mother yesterday...with him – like so many of these kids...it’s not the mothers being mothers...it’s the grannies, the aunties...women. Other women. His aunty would come and visit and he thought she was his mother. So when his real mother died – it made no impression. I don’t think it clicked that she was the real mother. To him, his aunt was his mother. I tried so hard with him...And then there’s situations like Gift’s...where no one wants him. It’s a challenging job...and you wonder – what is going to happen to these children?’

Gift was in limbo. There was rumour that someone from his father’s side of the family was going to come to fetch him from Kimberley. There were sparks of hope in the form of phone calls, but no one ever materialised to stand in as a guardian. Victoria and Khaya did not want

to put him in the care of his grandmother because she abused alcohol. So, like others at BCH, he waited. The waiting is discussed further in the following chapter.

An Education in Care

Whereas chapter 3 detailed the pill consumption and other processes that rendered a responsible child patient, the following conversation with Grace evidenced not only the responsibilities children are given, but those that adults shirked. Grace adamantly advocated for children as role models to adults: both caregivers and patients at BCH alike.

‘So as I said, you only notice something when you get into that something... I didn’t know children could be so sick with TB. It was such a surprise to see kids with TB. It’s not spoken to. Big patients think it’s only big people that get TB...they don’t know little people are more vulnerable to it than they are even...so with their surprise...they see the kids are happy and yet they still are drinking their pills. I think it motivates them sometimes too. If a child can take those tablets, as bitter as they are, why can’t I? I’m an old person...I’m supposed to be a responsible adult...and some of these older patients really look out on the kids and it changes their personal ideas about their own treatment. If they do it, let me do it. Children are role models.’

Grace’s comments about the lack of visibility of paediatric TB relates back to the introductory chapter, the ‘silent epidemic’ of childhood TB and incidence in the Western Cape (Soeters et al 2005). Although Grace felt children were responsible, she felt responsibility had to be nurtured when it came to caring for others beyond the individual self.

K: ‘Do you think that some children help to care for each other here?’

G: ‘They need help in this department...Theresa is always on that tip. The older ones must take care of the younger ones. They are all different and come from different backgrounds, circumstances and different ways of living...most of them do come from lower income families, sure. But they’re not the same. *They need an education in care...*you know. Some are really aggressive when they come here. They sleep in the same room, they eat from the same pot. This means you are brothers and sisters. Big ones take care of small ones. And that’s it. As long as you are here, you are part of a family and you have a home. And they need to be taught to know that. They don’t get it at home...the attitudes is aggressive, combative and sometimes violent towards other children. This is one big hospital family.’

‘I would say most of them are really troubled. I can’t say coloureds are more aggressive than blacks, or vice versa. It’s across the board. Even if we did have white children here, there would be issues. They’re kids – but they have some baggage from home.’

Here Grace made a clear distinction between a child's real home and BCH as a temporary site of home-making, similar to sentiments expressed in Chapter 3. Despite Theresa's sentiments that 'BCH was not a home', Grace felt differently. The following excerpts draw heavily on Fassin's (2013) ideas around the construct of the child as a recipient of humanitarian aid discussed in chapter 5. Children can be understood as beneficiaries of assistance, love, care and concern if adults are understood as negligent, irresponsible and potentially lascivious. When Grace speaks to the environments children are exposed to she includes the social, biological and historical effects that bear an imprint on the present in townships in Cape Town.

'They live in crowded places and there is always a lot happening. Even with my baby girl. We don't swear at home, we don't fight. But what happens is this: she knows how to swear – because the people right next door swear and fight. She knows how to be aggressive because they argue and physically fight too...these places are too crowded the townships. It's a big mess. Everything is just so messed up, broken into a million little pieces.'

'These circumstances are really messed up. We work hard. But it can feel like a losing battle. The system is broken and the health of the people is broken. You can't fix it. You can try and you'll go mad. Look at the crime rates. These type of children grow in spite of not being cared for or loved. They go out and satisfy themselves with things that aren't satisfying. This is why the crime rate is so high.'

Grace's observations took on a morally-coded language. The moral economy of child-rearing, responsibility and the uncertainty of children's futures is explored in other works (Scheper-Hughes 1994, Henderson 2009, Bray 2004 ci Marshak 2013:43-44). In contrast to the fear moral panic presented in these works and the scaffolding Christian teachings may provide a moral citizen, for Grace, education and independent thinking were key in caring for children. These were components in the moral imperative she felt towards teaching and nurturing children. Whereas all three teachers were guided by individual spiritual beliefs, their teaching was not contingent on Christian principles that Marshak speaks of in Bulembu (2013:59). Grace in particular drew upon a child's rights framework as discussed previously.

'That child was brought to life by you...they never asked for it...they didn't say "please put me on the earth just to suffer". You have to take responsibility – this is the 1-2-3 of being a parent – whether you like it or not. You had a choice. Your child has rights – just as anyone else does...especially here. You are obligated to do so as a parent. People need to make better choices for themselves...planning pregnancies, building a family. There are so many kids not being taken care of...they aren't given an education and independent thinking. No more of this make a baby and get a grant business. Show me the person who can have a child and subsist

on one of these child grants⁸⁰- or even the care grant when they are sick here...no one can do that my dear. No one.'

'These things ain't right': Violence in the Ward

The school space also served as a place of mediation. Negative events which took place in the ward were discussed in school. In my first few months of field work, an employee hit Themba in the back of the head, because he was 'being naughty'. It occurred a second time within the same afternoon. I immediately spoke to Dr. Early, and not surprisingly, older students reported to the teachers the following morning. Rosa was the first to explain to me that, 'These things ain't right. You mustn't touch the children, *mos*. We have our own mothers and father nuh? That man (the cleaner responsible) mustn't do that. He did that thing before (hit a child), it's not right.' The incident was relayed in a similar fashion to Theresa. She explained to me, 'This isn't the first time this has occurred. You get employees who are either contract or they work in the children's wards while others are on leave. They don't know how to respond to children acting out.' The incident was reported to the necessary staff, and the cleaner was removed. Rosa told me, 'He did this a long time ago too. He could lose his job.'

The conversation at school shifted to corporal punishment in the outside schools. Every child explained how teachers or headmasters/mistresses were strict. Some hit children. Sierra explained that her teacher hit her on the hands with a copper pipe when she was naughty. Nkosi was hit with a switch at his school. Zwai was pinched on the flesh near his armpits and Themba continued to talk about getting a 'klap' from the cleaner at BCH. Some of the children elaborated on the different methods of corporal punishment employed by their teachers. Rosa demonstrated the flicking motion the teacher made with a ruler across her hands as she laid them palm down on the desk, exposing her knuckles.

Theresa brought up the concept of trust, and asked the class, 'What is trust?'

'Trust means you believe in someone and they believe in you.' - Nkosi

'It means you feel safe.' - Rosa

'It means there's no lying to someone....and you can feel nice.'

⁸⁰ ZAR 240 per month, See: TAC Equal treatment magazine, special issue on Social Grants (2009) Issue 7 http://www.tac.org.za/sites/default/files/equal_treatment/2012/ET27English.pdf

‘When you trust in someone, you can make so.’ Gemma extended her pinkie to share a pinkie promise.

I asked children if they trusted Teachers Theresa, Grace and Candice. My question was met with an exuberant ‘Yes!’

Nkosi’s response was particularly thoughtful:

‘There are adults you can’t trust, you know. They’re the bad ones...These teachers by Brooklyn, they are the best. We feel safe. I feel loved here. I learn from books and work that we do. But I also learn to be good. To do good. That’s more important to me.’

On one of my last days of research, I stood with Theresa on the stoep. It was a sunny November day and the heat was beating down on the Ward three children as they dashed in and out of the sprinklers during recess. Theresa remarked, her hand holding her chin thoughtfully:

‘I just pray that they have good teachers Kate. If they have good teachers, they can go far. But if no one cares...not mom or dad or family. Who will look out for them? That is my wish.’

Brooklyn School was perhaps, beyond any other observations, a sanctuary. Those employed there were the guardians and providers of care through education, albeit not necessarily through academic channels. Children were formulated as beneficiaries of care, role models, but resilient in their own right. Brooklyn School was a site of healing, learning and comfort which was a world apart from the hospital according to Theresa, and different to a normal school in a number of ways. Grace’s sentiments framed children as students receiving an education in care: how to care for themselves and for each other in the face of an uncertain future.

The following chapter also focuses on care, but from the perspective of volunteers at BCH. Here, children are configured very differently than they were by their teachers. Overseas volunteers spent time with the children and contributed in a positive way through service learning at BCH. Their assumptions about sick children and what it meant to be in ‘Africa’ lent particular weight to their interactions with children, and how children understood their presence at the hospital. Children identified adults at the hospital through their roles and responsibilities, by what adults *did*. Volunteers were a confusing group of people for Brooklyn paediatric patients because they struggled to identify the singular role of the volunteers. Volunteers were neither paid employees, nor were they health care workers. The dyadic relationship between child patients and volunteers added to the therapeutic landscape of

Brooklyn Chest and brought to light the stark contrast between intention and consequence of working in a clinical space when one is an ‘outsider’ who wants to *lend a helping hand*.

Helping Hands: Care Safaris and Service-Learning Tourism

‘I don’t know why they are here. Don’t they have black kids where they came from?’ –Rosa

A group of day volunteers departed the Brooklyn school. A mass of donations stood in their place, a testament to their visit: stationary, sweets, toys, second-hand clothing and personal hygiene packets.⁸¹ Donations like these were common, and the gifts almost expected. There was a tacit connection between new visitors and gift distribution. I witnessed visits like these on many occasions, but unlike previous visits, a conversation emerged focusing on the different people children saw at the hospital. I wanted to know how children perceived adult roles at BCH. The conversation shifted from the predictable responses of adults the children interacted with daily: ‘nurses’, ‘doctors’, ‘you’ (Kate), ‘the TB people’⁸² to Rosa’s response: ‘All these white people’. It was true that the majority of the doctors at the hospital were white, but when I asked for clarification the group made a distinction which caught me by surprise. The differentiation of ‘white’ versus ‘non-white’ categories hinged on whether the individual was perceived as either ‘play’ or ‘work’ oriented. While some white people, like the doctors, were at BCH to work, many were not. Non-white people were, according to children, ‘always working at BCH’, while other white people were present ‘to play with us’. Children placed me in the non-white category due in part to the fact that the children saw me on a regular basis and that I spoke isiXhosa.

Children explained that doctors ‘make us get better’. Nurses ‘give us injections and give us our pills.’ Sometimes, nurses would yell at the children. ‘They say like this Kate: Sela ipillis⁸³ man!’ screamed Zwai as he impersonated one of the nurses. There was a distinct understanding about BCH staff roles and these roles aligned with race and job function. However, according to the children, volunteers were an ambiguous category of people. They were temporary, but present, and often came bearing gifts and wanting to play. Some children did not understand their role, Marissa’s sentiments illustrated this point. As she explained, ‘They’re the volunteers *mos*’. But I don’t know why they are here. What do they do anyway?’

⁸¹ See Norris (2012) work on second hand clothing and philanthropy

⁸² Desmond Tutu foundation staff

⁸³ ‘Drink the pills’ in isiXhosa

Younger children provided practical responses grounded in their experience with volunteers.

‘They hold us and play with us.’

‘They give us things.’

‘They buy us things.’

‘We play with the toys that they bring.’

Marissa did not ‘think they were lekker (nice)’. Zwai said ‘I just don’t like when they yell. Agnes⁸⁴ yells. She don’t (sic) like Xhosa, or Afrikaans. Only English.’ Nkosi was indifferent. ‘They give us things, they’re nice to talk to sometimes, but it’s always English, English, English. I’m not a child, I can speak. I don’t see how they can come here to BCH. Do they have jobs? Where does their money come from?’

Rosa and Nkosi’s observations influenced my desire to interact with volunteers and talk about their motivations for service work at BCH. Children’s understandings of adult presence in their lives were aligned with their role or professional function, by what the adults ‘did’. Volunteers, from their observations were a strange sort of visitor because their sole function was to play, buy things and give them sweets. Questions and observations like Nkosi’s compelled a deeper investigation of the volunteer landscape at BCH, how it related to the social life of the hospital, the people who interacted with patients outside of the hospital staff, and the motivations behind volunteering in general.

Theorising Volunteerism

This chapter explores the flow of ‘all these white people’, as Rosa called them, and their motivations for volunteering at BCH with sick children. Here I unpack their preconceived notions about South Africa and their understandings of their work at BCH. This chapter underlines children’s perceptions of volunteers and in turn, how volunteers contributed to a moral imaginary of the child which echoes concerns around language use in chapter 2, and draws upon historical charitable organizations in the introduction. In this chapter, volunteer narratives frame children as innately vulnerable and undeniable recipients of care, ‘love’ and material gifts. Although volunteers had little to no knowledge about TB, its aetiology or the effects on paediatric patients being treated for TB, the service-learning volunteers

⁸⁴ The eldest and repeat volunteer in Ward 3

differentiated themselves from other volunteers in that they genuinely wanted to *lend a helping hand*.

Service and volunteering have deep historical roots in Africa, which can be traced back to countries which export such service-oriented ideologies (Patel et al 2007). Communal practices in Africa were evident in the pre-colonial era, and the British colonial traditions influenced and shaped multiple domains: service, education, medicine, religion, economic policy and political rule (etc.). Although there is a prolonged history of religious-based and missionary service in South Africa and in Africa as a whole⁸⁵, the focus here is on secular volunteering, as the participants were not affiliated with a religiously-associated body. Globally, volunteering and service-learning projects are a growing field of inquiry (Moore McBride et al 2003, Patel et al 2007). Preliminary research on service-learning and volunteer programmes in South Africa (and in the southern African region) demonstrates that these types of programs could potentially make significant contributions to social development (Patel and Wilson 2004, Patel et al 2007). At the end of Apartheid in 1994, South Africa actively incorporated service into national social development policy (Perold et al 2006). Everatt and Solanki (2005) recognised volunteering as a ‘growing phenomenon’ in South Africa and correlate it with a growing civil society *globally*.

Volunteering and its various branches have only started receiving academic recognition over the past decade. However, much of the literature available is largely produced by NGOs and international volunteer organisations, which is problematic given the embedded bias (Patel et al 2007). Only recently have academics shifted their attention to the experiences of volunteers and the transformative possibilities with volunteer abroad programmes.⁸⁶ Even less scrutinised is the impact that civic and volunteer organisations have on the populations they purportedly aim to assist. The chapter aims to fill this void by trying to unpack volunteers’ knowledge, perceptions and motivations to volunteer in the first place, and the perspective children maintained of volunteers they interacted with. In agreement with Sin (2009), there needs to be a more critical scholastic engagement with those who are ‘recipients’ of volunteer and voluntourism efforts, especially in developing countries like South Africa. The scholarship I have in mind addresses power relations, privilege and notions of responsibility, altruism and ‘self’. Sin’s work encouraged foregrounding the ‘self’ as a way to theoretically deconstruct

⁸⁵See Vaughan (1991), Comaroff (1993) and Good (2004)

⁸⁶See Akande & Slawson (2000), Smith (2000) and Mathers (2004).

motivations behind volunteering in a foreign context (2009). For the scope of this chapter there is no distinction made between civic, service-learning, and volunteerism, because those who interacted with children ‘from the outside’ used these terms interchangeably. Baseline definitions follow; however the chapter argues that the underlying assumption across the spectrum of definitions is shared. The assumption of all BCH volunteers was that they were *able to help children in some way*; if they had not been in a position to donate time, clothing, toys etc. what were they *doing* there? This idea is firmly anchored on another presupposition: that sick (non-white) African children were in need of assistance. Therefore, children, in this rendering, exist to receive care, love and material donations. Children are figured as a component in ‘self-making’ experiences for volunteers.

Literature suggests a strong relation between social class, race and volunteering, in addition to more privileged socio-economic and educational backgrounds of volunteers (Flick et al 2002, Voicu & Voicu 2003). At the heart of volunteering is an inherent sense of philanthropy or ‘helping out’ (Patel et al 2007:10). The work is unpaid and incentives do not come in the form of monetary remuneration (although this is an area that is hotly debated).⁸⁷ The term *civic service* is not well theorised, but is used ‘to describe a range of service initiatives that include volunteerism and take account of forms of local, national, and international service that are emerging in the context of globalisation’ (Patel et al 2007:9). In another work Patel (2003) explains that far from being neutral, political, economic and ideological frameworks help shape civic service and its objectives, and there is no monolithic vision of civic service. Volunteering and volunteerism are better defined and feature far more prominently, although transnationally and locally definitions vary greatly. The United Nations defines volunteering broadly: ‘contributions that individuals make as a non-profit, non-wage, and non-career action for the well-being of their neighbours, and society at large’ (United Nations 2001). This definition includes volunteerism as a service that may potentially address social, economic, cultural and humanitarian issues (United Nations 2001).

Premised on a form of travel that is more benign than large-scale, commercialised, ‘mainstream’ tourism, ‘voluntourism’ is an increasingly en vogue term and concept. Voluntourism markets itself as being more beneficial to a targeted local community and potentially the ecological environment. Voluntourism is often situated within alternative

⁸⁷ See VOLSA (2004)

tourism or eco-tourism branding (Wearing & Neil 1997, 2001, Wearing 2001). Many theorists maintain that positive changes, transformation and greater consciousness are characteristic of voluntourism experiences, whether it be on behalf of the host community or the voluntourists themselves.⁸⁸ BCH volunteers never defined themselves as anything other than service-learners or volunteers. Whereas they did not self-identify as ‘volunteer tourists’, they described their programme as ‘service-learning’.

Service-learning can be defined as:

‘[a] method under which students learn and develop through active participation in thoughtfully organized service experiences that meet actual community needs, and which are coordinated with a formal educational institution to address and support an academic curriculum’ (University of Colorado 2005 ci Sin 2009:482).

Again, despite the differences between the definitions provided, the basic formula remains the same: travel + volunteer work + an identified group of people in need of assistance. In an African and specifically South African context, given abundant racial, social, material, and economic inequities, specific considerations are brought to light. The majority of volunteers at the hospital were American, which led staff members to formulate opinions (and often stereotypes accordingly).

Are you a *good* American or a *bad* American?

Throughout the research, there were different adults who volunteered at the children’s wards. All (except one volunteer) were white, female and either European or North American. There were numerous volunteers I came into contact with, and it would not be an exaggeration to describe BCH as a heavily saturated *volunteer space*. As a result, children were very ‘volunteer-savvy’. For the scope of this chapter, I present the experiences of five service-learning volunteers. In addition, three European volunteers feature briefly, one of whom, Agnes, volunteered at BCH for many years. The children didn’t always know *why* they were there and they did not always appreciate their presence. Slowly I learned that children distinguished the various groups through their own perceptions of ‘what adults *did*’. Although the perceptions of the volunteers changed in accordance with the age of the child, they had

⁸⁸ See Broad (2003), Uriely et al (2003), Campbell & Smith (2006), Cousins (2007), Zahra and McIntosh (2007), Sin (2009)

similar perceptions of what volunteers ‘did’, and this was how they identified adults in addition to personal characteristics.

When the new academic school year commenced in January of 2012, I returned to BCH to meet with Theresa. Previous to my arrival during the 2011 school year, there had been two American university student volunteers at the school. According to Theresa, they were domineering and ‘did whatever they wanted to’. They helped facilitate (and pay for) activities, and were very loving towards the children. Still, they interrupted the daily routine Theresa envisioned for the school and there had been much conflict. Theresa explained with a chuckle how, on our first meeting, she was ‘fed-up with American students’. ‘I thought you were one of them, oh Lord’, she explained. Unbeknownst to me, Rosa told her, ‘Juffrou (teacher), don’t worry, Kate isn’t like them. She’s a good one.’ With the children’s seal of approval and Theresa’s consent, I was allowed to accompany patients to school and assist (where possible) in the school space.

In mid-February, the university school term commenced and four volunteers started their service-learning projects at Brooklyn. Theresa hesitated in providing initial access, but she eventually relented in the middle of March. All four students were in their early 20’s and North American: Marita was Canadian; Jess, Carla and Stefanie were American students. Marita was a carrier for latent (inactive) TB, but none of the volunteers possessed substantial understanding or knowledge of TB. All of the volunteers were self-described ‘seasoned’ volunteers, having participated in other service-oriented projects in less-developed and impoverished contexts. In addition, all of the volunteers had previous experience with children and the programme facilitator, Jameela, supervised their desired activities at BCH.

Over the course of their service-learning, volunteers were present two to three days a week in the mornings during school hours. Jess worked with another volunteer in Ward B, while Carla, Marita and Stefanie volunteered at the BCH School. Initially, I wanted to develop focus group meetings to discuss the challenges, motivations and experiences they had both individually and collectively. Unfortunately, the focus group never materialised because of scheduling conflicts. Instead, volunteers answered my questions via emails and during their service-learning time. I wanted to know how children perceived these volunteers and how volunteers came to understand their role at the hospital. What motivated their desires to work within a clinical environment and to assist paediatric TB patients?

Imagined Africa

‘Africa is to be pitied, worshipped or dominated. Whichever angle you take, leave the impression that without your intervention and your important book, Africa is doomed’ –
Binyanga Wainaina (2005:92-93)

South African anthropologist Kathryn Mathers argued that media representations of Africa are largely lumped into one of two categories (2004). The positive category includes anything involving wildlife, safari or a ‘traditional’ way of life with ‘indigenous’ people in a pristine, rural environment. The other polarity, the ‘bad’, largely reflects AIDS, *the Dark Continent*, unabated violence, tribal warfare, corruption, and exotic, communicable disease. Wainaina’s infamous essay *How to Write About Africa* (2005) critiqued these stereotypes with scathing sarcasm. However cynical Wainaina’s criticisms may read, volunteer interviews and their preconceived notions epitomised his concerns about representations of Africa. Mathers (2004) explored this in her ethnographic work with American study abroad students in South Africa specifically. Mathers found that American representations of Africa helped mediate experiences of travelling and studying abroad for American students in South Africa.

‘Before arriving in Cape Town I was painted a very frightening picture of Southern Africa. My mother continually spoke of Cape Town as dangerous, dirty, disease ridden and destitute. However, not everyone described Cape Town in such harsh terms. In fact, many family members and friends lit up when I told them I was studying abroad in Cape Town. Their excitement was usually followed by a thirty-minute rant about the amazing experience they had and the wonderful people they met while studying abroad. Such differing opinions left me confused and unsure what to think about South Africa.’ - Stefanie

‘I originally got many “why would you go to Africa when you can go to Europe?” responses when I told people I would be studying in Cape Town. This especially came from my extended family, most of whom have not left the United States. My parents and siblings, all avid travellers, were all very supportive and knew I wanted to go somewhere *off the beaten track* of the traditional study abroad experience. My friends all know that I have a sense of adventure and passion for volunteering that Europe simply wouldn’t quench. I think people have very skewed views of what “Africa” really is like. I definitely had a skewed view as well, because all you see on the news and in books is how rural and unsafe Africa is. I think this is why my extended family was reluctant to see me come here – they didn’t know any better.’ –Carla

‘I have *always* wanted to come to Africa. I have been lucky enough to travel around the world, and to every continent except Antarctica, but Africa has always been a dream – I don’t know exactly what drew me to it, but I knew I wanted to study abroad somewhere in the continent before I even applied to college. The more I researched, the more perfect South Africa seemed for studying abroad. I still feel like I need to see so many more countries in Africa, and compare

and contrast them to really get a feel for what Africa is like. I think people (including myself) lump Africa together as a country instead of a dynamic continent and I still want to see what makes it so diverse.’ - Carla

While the volunteers’ statements appeared cognisant of media representations conveying one monolithic view of Africa as a country (Wainaina 2005), their sentiments were paradoxically representative of both the stereotype and the perpetuation thereof. For volunteers, Africa was a travel *dream* realised, an authentic aspiration of diversity and adventure. As Carla alluded in her response, many Americans just ‘don’t know any better’, but she distinguished herself from others via ‘a sense of adventure and passion for volunteering that Europe simply wouldn’t quench’. At the heart of her narrative she located Africa within her own (and collective public?) imagination, a place off the beaten track, where she potentially could *really* make a difference. In her conception, Europe was *just* Europe, Africa – something completely different.

Agnes’ thoughts differed from the American volunteers because she had been volunteering at the hospital for five years at the time of research. The two volunteers she invited to BCH to volunteer stayed for one month, but only volunteered one morning a week. ‘For me, this place is home away from home’, she explained to me. ‘I know the people, the children change but, no matter. I like to spend summer here because it is winter at home and it is too cold.’ The two ‘mentee’ volunteers explained, ‘We are having fun here. It’s a holiday...’ They too complained that the winter was far too harsh at home, and it was ‘nice to spend time at the beach in February’.

In another interview I asked the volunteers what they thought about Cape Town after they had arrived. I wanted to compare the expectations to the realisations after they had settled in for six weeks.

‘My initial impressions of Cape Town were similar to what I had expected. An exciting mix of European and African influences all at play in a vibrant city. I was slightly surprised at the extent of race relations and the role they play in everyday life. I thought they would be slightly more subdued.’ –Marita

‘I am so in love with Cape Town. Living in Bolivia, I always felt like an outsider. Because of my skin colour, language barrier, accent, etc. it was easy for people to label me immediately as someone who didn’t belong, but in South Africa, I love that I can walk down the street relatively under the radar. Initially I couldn’t see the poverty I’d read about (as I’m living in Rondebosch) but after visiting our potential service sights and doing a township tour it was amazing to me how much inequality really exists, literally divided by a fence.’ - Jess

‘My first impressions made Cape Town seem the complete opposite of what my mother had described. After the initial thrill of meeting new people and trying to get oriented in a new house, little cultural and societal characteristics of Cape Town started to appear. I did not notice the racial divide between blacks, whites and coloureds before going to Camp’s Bay Beach. A barrier of rocks divided the beach, one side was majority black and coloured while the other side was predominately white. Segregation became quite apparent in other place too. While at The Pig and Swizzle, a Rondebosch bar, I noticed blacks and coloureds drinking at one bar and whites drinking at the other. The segregation has been hard for me to grasp. Despite all imperfections that plague the United States, there is a far larger effort to cover up such racial and social separations. Here in Cape Town racial differences are not sugar coated or hidden. Additionally, growing up I never had to face issues of race. I was always in the majority where segregation and unequal opportunities did not exist or were not apparent.’ -Stefanie

‘It was definitely different than I expected – in a good way. Cape Town was much more modern and developed than I thought “Africa” would be. I was shocked to see that I could get everything I needed here – even my program made it seem like that wouldn’t be possible. I have been here 7 weeks now and realize how different South Africa is than the U.S., even if it isn’t obvious at first. Everything here is much slower (which has been nice) and more relaxed. People are also a lot friendlier. I think it is the most beautiful country I have ever been and I can’t get over the dichotomy between the beaches and mountains, rich and poor, races and ethnicities, cities and townships. SA continuously intrigues me with its rich culture and diversity.’ - Carla

‘Touring the township was another eye opening experience. I have never seen abject poverty in such close proximities. I have been describing what I saw to family by comparing it to the slums depicted in the popular film “Slum dog Millionaire”. Even with poor conditions people seemed *content and happy*. The people we met were *so strong and hopeful* which was truly inspiring. However, I left feeling like a hypocrite. How is it right for white affluent college students to take a tour of someone else’s life and destitution? I was comforted in being told by our tour guide that the people of Langa wanted outsiders to know and understand their life. I left feeling guilty for all the wealth and opportunities that I have been offered throughout my lifetime.’ –Stefanie

Lending a helping hand

The concept of volunteerism originated in the seventeenth-century Lockean notion of a self-organizing society which existed autonomous to the domain of the state. Alexis de Tocqueville’s work *Democracy in America* expressed the link between voluntary action and later, democracy (ci Anheier & Salamon 2004). Inherent in this notion is a political awareness, social solidarity and desire to help others. Still, volunteering for a specific cause cannot be considered *solely* an altruistic pursuit, given a variety of factors. In an increasingly competitive academic and professional environment, volunteering for different causes ‘looks good on a

resume' and can also contribute to experiential education. Sin's (2009) work with a service-learning programme in South Africa suggests that rather than crafting youth who are passionate about community service and assisting others, these programmes are a vehicle for travel abroad and going overseas.

'I sought out a study abroad experience based in volunteering because I wanted to do *something worthwhile* with my 6 months away from home that didn't simply revolve around university courses and partying. I don't have any illusions about volunteering that I am in some way "saving the world." In fact, I detest the condescending and patronising air of many international service initiatives. It's difficult to balance the role of helper and learner, and yet, I seek to learn and in *some way benefit the children and hospital before I leave*, whether that just be *through lending a helping hand* to the nurses every now and then!' -Marita

'*I hope to be a helping hand in whatever way I can*. Be it for the children as well as the nurses and teachers in whatever way I can be.' -Stefanie

'I eventually want to work in global health, either being a paediatrician working in 3rd world clinics, or as a global health specialist. *I thought BCH would give me exposure to some of the things I will be seeing*. I also thought it would be an incredible way to be immersed in the community and with citizens of SA.' -Carla

The essence of volunteering is partially philanthropic – one donates time and effort in a bid to assist or help someone else – but the volunteer also stands to gain something from the experience. As evidenced through their responses, the volunteers at BCH wanted to 'help', 'lend a helping hand' in the 'third world' 'for the benefit of the children'. Children (and what they desire) and the volunteers who aim to assist are fundamentally positioned and figured in a way that goes unquestioned. The children require the benefit of volunteers who have resources (whether intellectual, physical or financial) to aid them *in whatever way possible*. Marita's response was notable because she perceived the experience as a learning experience; she too stood to gain *something* in return from the children other than medical experience, which Carla alluded to in her comments.

This is where links between service-learning and voluntourism take on an additional dimension. Although both seem premised (and are marketed accordingly) to ideals like goodwill and service (Stoddart & Rogerson 2004), the potential benefits to the volunteer worker cannot be overlooked and are, in fact, key motivators for involvement. Sin's research reveals that:

‘...key motivators often revolve around the “self”, most explicitly stated in section headers starting with “I want to. . .”. Also intrinsic in this focus on the “self” is the comparison with the “other”, where the “other” could take on a range of characters, from the “other” volunteer tourist, the “other” peer or member of volunteer’s society who do not have a volunteer tourism experience, or the “other” encountered in the volunteer experience—the locals in host-communities’ (2009:488).

All of the volunteers I worked with were in some way or form crafting and forming parts of their ‘self’ and actively shaping parts of the ‘other’. Anthropologists have long given consideration to ‘the Other’; in Africa the construction of this category was by necessity non-white and accompanied a range of negative stereotypes.⁸⁹ At BCH, the ‘other’ was the paediatric TB patient, and arguably the figuration of *the African child* was an incredibly strong motivating factor to volunteer. Still, the service-learning project was more formalised than Agnes’ initiative, which for all reasonable purposes was a personal arrangement between Agnes, the BCH superintendent and Dr. Early. The following section examines the structure of the organisation CSL and volunteer motivations behind working with hospitalised children.

‘I knew volunteering would be easier here’

All of the service learners made their decision to participate in CSL based on positive feedback from former students, links to international initiatives, and academic incentives. As Stefanie explained:

‘I have always been involved with service and thought it would be nice to do while abroad...also, through the capstone project I can participate in all levels of research, hands-on community based fieldwork and design of a continuing viable service to those in need living in the community’.

For Carla, the fact that CSL was ‘an approved program by my university’ lent added value and she had ‘heard good things about it from students who had done the program in the past.’ She added that ‘They said that the program kept you safe, provided you with good opportunities to immerse yourself in South Africa and was overall a good experience.’

When I asked each service learner individually about CSL’s goals, Carla offered the sole response:

⁸⁹ Most recently Nyamnjoh (2012, 2013) has problematized this concept in academia. See also Devisch (2011) and Englund (2011).

‘I think CSL encourages students to become immersed in South African culture, and enjoy all that Cape Town has to offer. They also encourage volunteer work – although they call it community engagement.’

In her opinion, CSL was first and foremost a tourism initiative for university students, and service came second. Again, Sin’s thoughts on the ‘self’ are valuable for further analysis (2009). If crafting the ‘self’ is foregrounded as a motivation, rather than dismissed in favour of altruism, the tensions between potential outcomes and individual development can be considered more thoroughly. Once again, a return to Nkosi’s question and Rosa’s observations about ‘all these white people’: *why* are they here, and *what* is it that they *do*?

A Crisis of Care

‘Conceptualisations of childhood are ultimately constituted by discourse’ (Norman 2012:249).

Norman draws on the central placement of children in the era of HIV/AIDS in sub-Saharan Africa, with particular consideration of South Africa because of the high burden of disease. In no way do I aim to make parallels between the two diseases, rather gesture to the ways in which they overlap. Essentially, the same can be said for TB discourse and the placement of children within it as discussed in the introduction. The ‘childhood in crisis’ discourse is circulated locally, nationally and globally and often displaces those issues which affect much larger populations of adults or other children in similar circumstances. In relation to HIV/AIDS, Chazan (2008 ci Norman 2012:252) calls this ‘AIDS exceptionalism’. The exceptional population group diverts attention from the (often times) far more severe issues (or at risk populations) at stake like food insecurity, domestic violence, and poverty. This type of exceptionalism, while not directly linked to HIV/AIDS, can be applied to major discourses related to bodily health and disease. Children become the sole focal point, the centre of attention.

Norman explains that children in South Africa are conceptualised as perpetually in a state of crisis (2012). According to her, this is not the first time black South African children particularly have been labelled as vulnerable or ravaged by the injustices of society. Previous works highlighted ‘lost childhoods’, or the inability for adult care-givers to provide care because of the migrant labour system.⁹⁰ In the 1980s, academics voiced concern over the

⁹⁰ Ramphela (1993)

effects of Apartheid's political and economic violence in South Africa: children often subsumed adult-like chores or responsibilities and many works detailed children having been robbed of their 'right to just be children'.⁹¹ Again, this figuration of childhood and what it means to be a child is based on a very specific, hegemonic understanding of childhood as discussed in Chapter 2. Against the backdrop of HIV/AIDS, Norman identifies the re-deployed 'crisis of care', where the nuclear family (and even extended family in some cases) is erased via the crisis rhetoric in circulation (2012). Context is discarded in order to make room for more 'vulnerable' groups and the accompanying urgent need for care takers.

It is my contention that 'vulnerable' populations (and *especially* children) exist within this framing of need for a very specific purpose. If there is a 'crisis of care', as well as a population *in need* of care, there will be a steady stream of those wanting to supply said care. Present a need, and the conceptual void will be filled with those desiring to fill that need. The 'crisis of care' Norman (2012) described circulated at BCH, but on a very small scale. I eventually learned that CSL participants were not allowed to work with adults, and while they had been given the option of four different service sites, working with 'sick children' in particular was an attractive offer, especially for pre-med students.

As Jess explained:

'Because some of us are social science/humanities students without a degree, we're not really qualified to work with anyone else. That said, I love working with children, I have such a passion for nurturing young minds, and given the choice would have probably chosen this age group regardless. I am especially interested in the effect TB has on childhood development, and the effect so much time spent away from nuclear family structures has on a child's social development.'

'We only had the option of working with the children. We had no options of working with the adults.' –Stefanie

Marita explained that she chose BCH based on the fact that she, 'loved kids... and ...thought we might get along well.' Carla also articulated her love of children and was '...drawn to a facility where I could work with sick children closely. There seemed to be a lot of opportunities at BCH to give back, learn more about TB and shadow doctors and the occupational therapists.'

⁹¹ Burman and Reynolds (1986), Jones (1993)

Amidst the excitement of working with children, volunteers expressed their preconceived notions and ideas of BCH as a service-learning site. Here, volunteers related their (imagined) versions of BCH and then compared those framings to the reality of their experiences. Their responses ranged from the ‘ease of access’ position, to questioning the degree of ethical reflection (some) volunteers assume when working in a service-learning environment.

‘I knew that I would have a lot more freedom with volunteering here than in the U.S. because the United States is very strict with guidelines, background checks, etc. I also expected the facilities to be very different from the U.S. and more simplistic. I knew volunteering would be easier and more rewarding here because there is more of a population to help than in the U.S. so, even though I love volunteering in the States, I was more excited to do it here.’ - Carla
‘Because I am coming from a 4 month, full time service program in Bolivia (where I worked on marketing for a day-care and women’s micro-enterprise) I think I expected a lot of disorganization. Coming from a hectic work environment with little/no resources, it has been so refreshing to see that the school, for example at BCH is so structured. In my last internship I was given pretty straightforward ideas as to what was really needed in terms of a project, but I don’t feel as sure about what I’m doing at BCH yet.’ - Jess

‘As a frequent volunteer, I attempt to carry out ethical practices of service at all times. I am very aware of the condescending tone that volunteering can take. I constantly try and avoid that kind of behaviour. I hoped that when volunteering alongside other students, they would also keep that in mind. And yet, my preconceived notions of some American students that I have volunteered with in the past have definitely come into play. I have often seen students take an “I know better” position, especially in situations of education and childcare. – Marita

Centring the Self

One of the central goals in this chapter is to argue for a more balanced critique of voluntourism efforts in academia. One such angle places the ‘self’ and ‘self-making’ central to BCH volunteer experiences. As Sin (2009) urged, self as a theoretical tool helps to engage new debates around tourism: social responsibility, active citizenship and the organisation of different volunteer projects. If voluntourism continues to be organised along apolitical lines, there is a risk of recycling the very social inequalities and structural violence voluntourism efforts aim to alleviate. The self a central component, because the self can only be organized in comparison to the ‘other’. In settings where health inequalities are blatant like at BCH, it is

an easy slippage to fall into because one is either 'sick' or 'healthy', a patient or a non-patient; the contrasts are stark and often divisive.

Literature relating to the 'gap year' in the United Kingdom demonstrates that international volunteering may reinforce existing stereotypes and deepen the 'self' versus 'other' or 'us' versus 'them' mentality of volunteers (Simpson 2004, 2005a, 2005b). Simpson (ibid) has suggested that many gap year organizations market a simplistic view of 'the other' so that differences become commodity. Other research⁹² argues that certain types of volunteer programmes may reinforce power relationships between developed and developing countries, thus representing a form of neo-colonialism. Raymond and Hall's (2008) research illustrates that although cross-cultural understanding and appreciation is an objective of volunteer projects and service-learning programmes, it may only occur at an individual level. In addition, there is not a one to one formulation between the individual and large-scale changes to perceptions about culture or nationality (Raymond & Hall 2008).

K: 'In what ways was this preparation useful? Beneficial or otherwise? For example: Is there specific advice which has been helpful in negotiating BCH?'

'The orientation was more informational about current issues of inequality in South Africa than having any real benefit in negotiating practical service at BCH. I mostly draw on previous experiences of volunteering (both internationally and at home) when carrying out service at BCH. However, it is interesting how issues of inequality and race relations come into play at BCH.' - Marita

'Preparation was very vague and to a certain extent I did not know exactly what I would be doing. This only made understanding my role in Ward B difficult. At the school there is much more structure and the teachers tell us exactly what they need.' -Stefanie

'I don't really know if we got enough information regarding the sites. I signed up for BCH over a month ago and just started on Friday. I also wanted to work 3 times a week, but CSL cancelled 2 of the days I signed up for, so now I may only be able to go once, which is disappointing. They do help us get to the site, and got us in contact with the people we will be working with, though, which is great.' - Carla

⁹² See Griffin (2004), Barkham, (2006) Brodie & Griffiths (2006) Frean(2006) McBride et al.(2006)

K: What were your initial impressions of BCH?

‘Honestly? I was scared walking into a fenced-in TB clinic. Even coming from an educated background, my knowledge of TB was lacking, and I was immediately afraid I was going to get TB. There is so much stigma around TB and most of it comes from a lack of understanding. I wanted to come to BCH to learn more about the health system as a whole, but also to learn about the developmental effects a child can experience as a result of living in a hospital setting at such a young age, and the effect such a transient lifestyle (people always coming and going) can have on its organization.’ –Jess

‘Before coming to the BCH Clinic I knew very little about TB and was in fact nervous I would catch it while volunteering.’ -Stefanie

‘I loved BCH. I didn’t form much of an opinion on the hospital right away, but I loved the children. For some reason, before I came to the hospital, I didn’t fully grasp quite how sick some of the children would be. In that way, the first day was hard for me, especially in Ward B visiting the extremely developmentally delayed children.’ –Marita

‘Coming into service I felt obligated to do everything in my power to fix the problems of the TB Clinic (BCH) or at least create some form of ameliorating solution. Unfortunately, I am learning that at BCH there are problems I will never be able to fix. In this instance, ignorance is bliss in the sense that before coming to Brooklyn Chest I never knew what extreme hardship these children are faced with. Most go home to families ridden with drug abuse, domestic violence and extreme poverty. There are a few girls who are returning to BCH for the 3rd or 4th time. Seeing the sickness, family situation and poverty that these children face has made me feel like an outsider. Initially my thoughts were, “where are their parents, how can they neglect and expose their children to such destitution?” Then I realized, who am I to judge? Who knows how I would react in their situation. Growing up with poverty and hardship would have made me a very different person and I will never fully understand the inequality and barriers they face. Often while working at BCH I have felt very helpless.’ - Stefanie

‘I am enjoying my time spent at the BCH and interacting with the children, nurses and teachers but leave with no idea where I can help. This is partially because I feel like an outsider at the BCH. The nurses, doctors and teachers along with the patients who make up the community, are often too busy to interact with us or give us a task. Additionally, when we ask a question the responses are either flat, if offered at all. At first, I thought they did not like me. I then realized that some of them don’t speak English well. However, I still don’t want the nurses or teachers to think I am questioning their power or stomping on their turf. Furthermore, we do not have much interaction with the doctors because there is only one doctor and so many patients to see. Thankfully, the children have made me feel more like an insider. They flock to us as we approach the gate and want to be played with and be held all day’ - Stefanie

‘I was surprised by how healthy a lot of the children seemed, but how sick others were. I couldn’t believe the range of illness of the same disease. I also was shocked that we were just able to play with the kids and interact with them. In the U.S. we probably would never be able to touch them and would just have to do background work. It was also so sad that a lot of the children do not get to see their parents a lot.’ -Carla

‘I’m here to learn, I’m here to give back, I’m here to grow.’

Aside from their weekly interactions with the children, service learners wanted to contribute to a project which would, in some way, become sustainable. Previous CSL capstone projects were not carried over subsequent to volunteer departure from BCH. The school library had been revamped and volunteers initiated a literacy program, but after the volunteers departed there was no continuity. Theresa, Candice and Grace were too busy juggling the day to day running of the school, and had established their own curricula. As discussed in Chapter 4, the school environment was chaotic, given an ever-changing set of dynamics: assimilation to different medicines, (lack of) correspondence with home schools, supply of necessary school materials etc. Jess in particular saw the school as the place where she could ‘make the most impact’.

‘I’m interested in providing more structure in Candice’s and Grace’s classes, possibly reorganizing the play room, and creating a set schedule for the kids to follow in the hopes of giving them more stability and purpose throughout their time here. I hope to speak with the school teachers about what they think the children need and maybe create set times for certain activities.’ – Jess

Stefanie was interested in initiating a therapy group or a space where children could ‘share their feelings’. She expressed interest in a Life Orientation after school programme.

‘Just a place for the school age children to talk and discuss anything they are dealing with that they may not want to talk to the staff about...I am up for being involved with anything that is beneficial to the children, school and ward B.’ - Stefanie

Carla, Jess and Marita focused their responses on *learning* from Ward 3 children. They positioned themselves in a learner role, whilst simultaneously placed children in a teaching role.

‘I want to form relationships with the children. I want to be able to go in every week and have them remember me and feel some comfort in having me there and I want to learn from them and try and understand more about TB and how it affects these gorgeous kids.’ -Carla

‘I’m here to learn, I’m here to give back, I’m here to grow. Because I volunteered in Africa over 5 years ago, and felt unsatisfied in the sustainability of my work, I am interested in continuing previous CSL student’s projects and building upon their work to make my time at BCH meaningful and helpful.’ - Jess

‘I hope they teach me about their experiences with TB. Since finding out that I carry the disease, I’ve become very interesting in learning about the different ways it affects people. The disparity in the experience between my carrying TB and their experience with the disease is extreme.’ - Marita

‘When caring can be harmful’

Whereas Theresa and the other teachers expressed their dismay with previous volunteers, there seemed to be minimal issues (if any) with the volunteers featured thus far in the chapter. Six years of working within the BCH school, Theresa, ‘had grown accustomed to doing things by herself, for herself, and for her pupils.’ She welcomed volunteers as long as they ‘stayed out of her way and filled in the gaps’. There was however one volunteer who Theresa prohibited from the school based on negative experiences.

Agnes was a retired social worker and ‘had a lot of experience with children’. She volunteered at BCH with the children in Ward 3 for five months a year. Every afternoon, she brought Lego blocks, cards and board games, most of which came from Europe. Our first few meetings were inexplicably tense and she continually questioned my presence in the Ward. She was strict and described by many nurses as ‘old school’ and ‘a taskmaster’. ‘There have to be rules Kate’, she explained. ‘These children must know who is the boss.’ I asked the other volunteers about discipline. Stefanie and Jess explained, ‘We’ve been told by our service-learning program to just sit back and absorb the children’s experiences, and not to come with ideas about how we think we should do things or how things *should* be.’

Yet, in contrast to the other volunteers, Agnes was a disciplinarian. Ward 3 could be a chaotic place, and if an argument or disagreement erupted she scolded children and took away toys. This punitive measure often resulted in fighting between the children. In addition to her time spent in Ward 3, she mentored two young Scandinavian volunteers for a month to ‘show them the different problems at BCH and in Africa’. Agnes prohibited children from speaking Afrikaans or isiXhosa in her presence. When I questioned the basis of her reasoning, she explained she ‘was too old to learn’, and furthermore she didn’t understand what was

happening when they speak their native languages. 'I don't understand what's going on if they don't speak in English'. She also added, 'If they speak in English I can help them better...to know what they're going through. If they speak in their languages I don't understand them.' Because much of the research was conducted in either isiXhosa, or Afrikaans, Agnes' 'English only' rule was counterintuitive to my personal and ethnographic ideals of communication. I continued to speak in Afrikaans or in isiXhosa to the children, and they to me. Agnes' goal and reason for being at BCH was 'to make the children better people'. She wanted to 'teach them what is right and what is wrong'.

I felt uncomfortable with the ways she enforced discipline through punitive measures and moral sentiments. One such altercation exemplified our fundamental differences. One afternoon dinner was being served up, and I noticed Gabi sitting on her bed, facing the wall, crying. Gabi had only been in the hospital for two months and experienced many of the negative side effects detailed in Chapter 3. She was also homesick and vomited on a regular basis, hence her unwillingness to eat too much food. Agnes entered the room and told me not to speak to the child. 'Kate, she is being punished. I'll ask you to stop speaking to her now.' I explained that I wanted to know why Gabi was being punished in the first place. Gabi interjected, 'Agnes said I was naughty, but I wasn't'. Agnes fired back, 'Yes you were child!' It didn't strike me as the place of a volunteer to discipline children, least of all through withholding a meal. Agnes eventually relented, and Gabi joined the other children at dinner. Agnes told me that I needed to know the 'proper way of handling them'. 'Children are not adults, you see? They need to know the difference between right and wrong, Kate. You are too young to understand and you have no experience. You are a silly girl.' Throughout the altercation Nurse Jones (who was on shift) said very little to mediate the situation.

The following day, I followed up the incident with Dr. Early. She thought Nurse Jones 'backed down' to Agnes because she was from a generation where older, white people were 'given an authoritative reign over certain things'⁹³. She explained further:

'This is an old problem of Africa; through the decades Africa had to take what volunteers came their way in terms of medicine, schooling, funding etc. Sometimes colonial paternalism has robbed them of their own culture, their own creativity etc. It is a problem.'

⁹³ This is a direct reference to Apartheid because both nurses are not white.

She specifically expressed concern in regard to Agnes' interactions with the children. She observed that Agnes was increasingly more controlling, and there was constant admonishment. Dr. Early wanted to institute a protocol which stipulated the roles of volunteers and that of staff personnel, but she wanted to be diplomatic simultaneously. Given the fluidity and numbers of people throughout the space, standard protocols were needed. She explained the chaos of too many volunteers, an increasing influx of new patients and a revolving door of medical students. She admitted she and other staff sometimes didn't know 'who was who'. The other visiting doctor voiced her concerns. Both agreed that BCH required a formalised volunteer application process. According to Dr. Early, some volunteers could do more harm than good. She cited circumstances where it was not advisable to 'handle' the children too much. This was especially the case for spinal TB patients and those with TB-M. She shared her concern about volunteers who were unaware of TB infection; walking into an adult MDR ward without a mask was a potentially very risky (and preventable) mistake. Dr. Early made it clear that if a volunteer was not 'filling in the necessary gaps' at BCH, they were technically not 'doing their job'.

I avoided Agnes throughout the rest of her stay at BCH. Many activities I tried to initiate she undermined. The body-mapping exercise in her opinion was 'silly' and 'inappropriate'. She explained that the children 'don't understand those things'. I later discovered she had also taken down the mood boards we placed in the ward. The last conflict with Agnes occurred in in early March, and the ward was sweltering. We sat in the shade outside and the children sucked on *bompies*⁹⁴. Zwai asked me for sip of water from my water bottle, which was almost empty. I passed him the water bottle only for Agnes to grab it from his hands. 'Kate – do you really think that is responsible? They have TB, you are going to get sick if you share water with them.' I replied, 'There's nothing wrong with sharing the last of my water.' 'No, Kate you are wrong. Don't get their germs'. Zwai asked me then in isiXhosa 'What's her problem? Why is she stigmatising me.' I replied, 'Everything is fine. Ignore her and drink the rest of the water, *boetie*'.

I remained active in the school until Agnes completed her time at BCH. The incidents with Gabi and with Zwai marked a turning point in the ways children spoke about volunteers, and

⁹⁴ a frozen dessert

they ways they spoke of Agnes particularly. The following day at school Zwai detailed his experience to Theresa:

‘She was stigmatising me man. I don’t like that old lady. She has her shiny toys. I don’t want them. She must go and play in Ward B with those little ones. I’m no baby, and I understand English. Kate, you will share water with me, nuh? I’m not infectious. I have TB in my brain. No one can get it’.

Gabi added, ‘and the way she talk, nuh? I can’t hear her proper. She always going ‘No, No, No’ (using a mocking German-sounding accent). Shah. Don’t speak that language! Wait Wait Wait...I’m talking to you!’ Others chimed in. ‘Yes, man – like that time when she said “You can’t play with my toys!” Yoh! I laughed at her! I’ll *praat* (speak) what I want!’ Rosa added. Nkosi explained, ‘We asked her why she don’t greet Kate. I asked her why she doesn’t like her (Kate)’. ‘And what did she say Nkosi?’ asked Theresa with a wry grin on her face. ‘Yoh, juffrou, she said “That’s none of my business”. Yoh, I laughed at her.’

Contrary to Agnes’ opinion that children were unaware, or didn’t *know* the difference between right and wrong, Zwai’s reactions proved otherwise. Her comments hurt him, and he was now made aware of the stigma associated with having TB ‘germs’. His statement demonstrated his understanding of his *own* TB, and the implications of infectiousness. Theresa explained to the children that they had a choice to play with Agnes, and agreed that she did not share her opinions. Theresa and the other teachers assured me that ‘everything was going to be ok’. ‘She’s just on her own mission...of which I don’t know what it is...reminds me of the colonialists, really’, explained Theresa.

Reflexivity as a Process and the Productivity of Discomfort

I return now to Rosa’s quote that introduced this chapter. Rosa’s articulation can be read in many ways, and warrants further consideration. Her statement about those who were ‘the helping hands’ and those who required help was both a rebuttal and an affirmation. She, at the age of 14, understood that most impoverished, sick children were non-white, and that other ‘black’ children the world over may suffer too, like she did. Suffering here inculcates assistance. I do not know if Rosa, who had never left the Western Cape, was aware that racism and privilege exist elsewhere, and in the same contexts in which volunteers called home (whether volunteers were aware of this or not, I cannot speculate). Additionally, she was making a fundamental statement about *who* stakes claims to provide care and why. Inherent to

these claims are basic tenets of privilege: distinguished by geography, history, race, class, financial means etc.⁹⁵ Rosa's sentiments also laid bare the contestations and confrontations experienced with volunteers at BCH.

Yet, sifting through the body of thematic literature yielded very little new information to weave into this conclusion. Moreover, very little of what I have read has addressed as poignantly my ongoing discomfort about volunteering with children in 'Africa' (Wainana 2005). I realised that this discomfort extends to Anthropology and my personal and professional stake in the discipline as well. Nyamnjoh's (2012) thoughts on *reflexivity as a process* help to consolidate my line of thinking here, but first, a personal aside.

The parallel discomfort lies in my previous participation in the NPO and NGO world in South Africa, which has left ideological scar tissue. A decade later I remain sceptical of foreign volunteer programmes in South Africa; and yet, here I am – an aspiring medical anthropologist, from North America, in a personal partnership with a non-white South African. My work focuses on those who are often targeted for conscripted need because they have TB, HIV or AIDS or, as is often the case, both. People I work with and their experiences are most often steeped in different types of traumas, be it historical, physical or otherwise. As discussed in the introductory chapter, caring is integral to the anthropological enterprise: it is what we *do* as anthropologists. Chapter 2 detailed the cause and domino effect of framing (and appropriating) children as vulnerable and inherently innocent. More often than not I found myself distinguishing between the volunteers and myself, refusing to acknowledge (or downplaying) any likenesses drawn from skin colour, country of origin or hair type⁹⁶. I actively sought to maintain a 'safe distance' based on opinions they expressed, of which only a fraction I have included in this text. I realise that I maintain this distance in the majority of my interactions with North American students in other personal and professional environments. I sought to stay autonomous to 'them', I simply could not relate. Perhaps one of the few baseline characteristics shared between volunteers and myself was the desire to help, or to care, manifest in the smallest of ways. Still, reflexivity cannot be distilled in a moment or a collective of moments: it is a process, and this chapter concludes on that reflexive note.

⁹⁵ Flick et al (2002), Voicu & Voicu (2003)

⁹⁶ Often teachers and children would joke about white hair and our similarities as 'white people'

One of the perpetual confrontations in anthropology is that of representation; *who* is representing *who* and with what legitimacy, expertise or authority? As Nyamnjoh explained:

‘The question of problematic categories such as “native” and “non-native” in anthropology remains unresolved, and distinctions between insiders and outsiders continue to be informed more by prejudices and preconceptions than by the objective reality of the lives of those so labelled. (2012:72)

As often as the formulation of ‘the other’ is cautioned against in classrooms as a categorical entity, or as a process (othering) in the field or in the everyday, I found that I emulated just that in my research, however minimally. Was it in a bid to disassociate myself from those that shared the same skin colour? A vaguely similar accent? Divergent world views or opinions of ‘Africa’? Perhaps none of these and all of them apply, I am not sure, but I know that the discomfort sticks to me still. Do I reproduce the very structures I seek to dismantle in my work? Am I not trying to do ‘good’ or help those I see as oppressed? Do I jeopardise dehumanising those I aim to assist via anthropological voyeurism? How is this process any different from the experiences of the volunteers presented in this chapter, if at all?

‘Few of us are ready to consider reflexivity as a process – something deserving of more than token mention in the prefaces, introductions and methodology sections of the books and journal articles we produce to justify our status and salaries. Yet it is glaringly evident that reflexivity as a process starts with the very conceptualisation and implementation of research. Reflexivity is not expected to take leave of one once one has taken leave of the field.’ (Nyamnjoh 2012:66)

Who is to ‘Do’ the Helping?

My personal scepticism gave way to individual reflection on altruism and how it evolved throughout volunteers’ thoughts on what *they thought they did*. The paediatric wards were a meaningful interface for many volunteers, and they did, for the most part, provide temporary gratification for the children they aimed to help. Volunteers sincerely felt they were making a difference, albeit a small difference, in the lives of the children of Ward 3. Agnes’ actions were not representative of the core, but the outlier: a generational, Eurocentric vision of what children *needed to be* for a specific purpose, her purpose. The following year when Agnes returned to BCH to volunteer, the hospital refused to provide her access. There had been too many conflicts, her presence was no longer beneficial to children in Ward 3.

In my grappling and grasping for a conclusion, one work by Marlon Burgess (2007) stood out. Burgess wrote about a similar volunteer program from the unique perspective of being both a South African from a previously disadvantaged community and his experiences working alongside American service-learning students. His writing sensitively grappled with his own ethical reservations when confronted with the industrial aid complex, well-intentioned volunteers and the desire to 'give'. He too noted the different ways of conceptualising 'work', 'help', and 'play' similar to the children at Brooklyn (Burgess 2007). In comparison to much of the development literature and the role of anthropology, Burgess allowed space for not only entanglement of structural embeddedness, political trauma and history of a place. He managed to draw out individuals and their expression of self via their altruistic (whether genuine or not) pursuits. He concluded:

‘...what I encountered was not a monstrous oppressor, or even a self-righteous philanthropist who unwittingly leaves disaster in his wake. Rather, I met thoughtful individuals who grappled with life from moment to moment...’
(2007:57)

I would like to *think* that anthropology (and anthropologists) are similar. Anthropologists often are involved in research that is uneven, in a bid to better the lives of those they work with, or calling attention to the plight of an oppressed group through their findings. Critical medical anthropologists (and there are many) specifically have sought this type of social justice, exposure and (academic) intervention.

Spiegel has explained that in South Africa:

‘...We should not lose sight of the fact that much of that research involves scrutinising relationships and structures of dominance and subservience between those who are dominated and those who dominate them. Part of the challenge for us in South Africa is to address the concerns of people who are dominated, and, unfortunately, Apartheid’s legacy is such that those people tend primarily to have black skins. So we end up focusing on their life experiences, which include the pressures on them coming from those who dominate’ (thoughts from Andrew Spiegel ci Nyamnjoh 2012:73).

Again, Sin (2009) argued eloquently for ‘self’ as a theoretical tool to address the structural inequalities in different types of tourism critique. The selves that were crafted during the volunteer time emerged in ways that were, for the most part, for the benefit of the children. Sin’s thoughts soften the harder debates so eloquently argued by Nyamnjoh (2012, 2013).

‘Today's acts of compassion are an avenue of self-expression and even a form of rebellion against the sterile repressive subcultures of government and business bureaucracies. People said they do good because it makes them feel good, gives them an opportunity to express caring sentiments, and is a way for them to get in touch with their humanity. In other words, voluntarism and compassion are ways for people to express their own individuality’ (Wuthnow ci Galaskiewicz 1992: 190).

Stefanie’s thoughts reflect this sense of self and purpose.

‘At first I was having a difficult time defining my purpose at the TB clinic. This feeling of helplessness and uneasiness about my role... The teachers and nurses commented on how nice it was to have us around, *we gave them a break and were a helping hand*. We also all agreed that the Ward needed more structure. The children are continuously anxious, unhappy and begin fighting with each other due to a constant state of chaos. Within this state of transition, the structure would allow them to feel like they know what is going to happen next.’

Didier Fassin (2013) recently wrote about what he called the humanitarian problematization of childhood in South Africa. As long as children are promoted as inherently innocent, humanitarian intervention efforts will continue to *speak for* children as perpetual victims. This figuration is particularly damaging to children themselves. Fassin warns that the moral economy can serve to deconstruct and illuminate the veneer of illusions intrinsic to much of humanitarian aid. I am not arguing against volunteer efforts or humanitarian aid on behalf of children or those less fortunate than the volunteers in this chapter, or myself. I do however feel that an honest appraisal of the stereotypes and othering tactics *we all* share can create and serve to interrogate more responsible and equitable service-learning programmes, both in and outside the confines of the university, in South Africa and elsewhere.

The next and final chapter discusses the nature of time in Ward 3. The ways that patients and staff spoke about time and employed time-related metaphors revealed the often tortuous and painful nature of waiting and the precariousness of existing in a state of continuous liminality. Waiting for discharge, waiting for a social worker’s report, waiting in uncertainty for an uncertain future. Time-related metaphors conveyed time as many things: a resource to be gained or depleted, the uncertainty of the future, or inevitable mortality. This type of time, and the ways nurses especially spoke to the unknown differ dramatically from the ‘type’ of time spoken of in chapter 3. In chapter 3, time was marked by a daily routine: structured by a scaffolding of pill drinking, injections, audiology tests, x-rays and reinforced through patient review sessions, protocols and idealised notions of biomedical ‘progress’. In a biomedical

sense, time is indexed by clocks, schedules, convenience, progress, and efficiency. Chapter 6 demonstrates another type of time. One that is floppy, resistant to the efficiency of the ward, but simultaneously vulnerable to the messiness of life circumstances and troubled times outside of the confines of BCH.

‘Time is all you have’: Ways of Speaking about Time, Burden and Liminality

‘Critical illness not only presents you with issues of finitude, but more importantly, it threatens the very foundation of time structuring by removing you from life’s comforting rhythms. It becomes a struggle not to *fall out of time*.’ (Emphasis in original Hagestad 1996 ci Stacey & Bryson 2012:5)

‘This MDR – it will kill you. We do everything for them (patients), and they don’t drink. The TB-Ms they’ll come in here and you don’t think they’ll ever walk out – but they do! Not all...but most, they sure do, you bet they do! And they should be dead. These drugs are good. But they take time to get used to...all of it does, but time is all you have here’. - Nurse Dee

The chapter analyses how children and nurses employed time-related metaphors at Brooklyn. Metaphors were ways of discussing experiences of the unknown, burden, tedium, and potential loss. Temporal references prompted a reconceptualization of Ward 3 children as those ‘with’ or ‘without time’. In this sense, children were ‘keepers’ of time, ‘subjugated by’ time and trying to ‘catch up with’, before ‘running out of’ time. Time as a resource metaphor and conversational tool merits conceptual revision to time as it was presented in chapter 3. In chapter 3 time was linear, process-oriented, and objective because biomedicine requires a temporal structure buttressed by routine and regimen. In this chapter, the value of time is understood through illness.

Conversations shared with nurses and children conveyed a messy sense of time. A notion or experience of time that was layered and looping at BCH. Epidemic diseases throughout history, especially TB, serve to remind us that progress is uneven, and that individual bodily experiences transcend time in any fixed sense. In this way, the *very structure* of time in a hospital setting must be questioned, as well as the experiences individual patients and nurses attributed to that structuring. The temporal structure and space at BCH became floppy, porous and far less rigid than the strictures of ‘biomedical time’ characterised by linearity and sequence in Chapter 3.

Resonant with the Hagestad quote above, BCH children were removed from the cadence of their everyday life: familiar rhythms which aided the structure of one’s home life and routine. One ‘falls out of time’, or out of synch, when faced with a critical illness. As Stacey and Bryson observe in relation to women’s experience of cancer, ‘Illness warps time’ to a certain extent

(2012:5). I argue that temporality is incalculably warped when one is a patient in a hospital environment. Here I apply Van Gennep's (1960) rites of passage framework, but I do so with caution. It is pertinent to note that the very patients or liminal characters (in his terms) that are rendered invisible by structural processes, foregrounded my research at BCH. It was, and remains the case, where the margins constitute the centre of a global epidemic.

Chapter 3 described biomedical modes of time keeping through various acts: the consumption of medicine, sleeping and waking times, school attendance and bathing schedules etc. and how they contributed to configuring the *child patient*. Structure was embedded in these matrices of routine, even in the face of a continually ambiguous chase towards a diagnosis. Science is theorised as chronological: tethered to predictability, an idealised outcome, or *eventual* cure. Control in the ward was imperative in order to attain any sense of a TB-free future for each child patient. Time (and all the routines which accompany it) produced the child as a patient. In this following chapter, time-related metaphors opened new possibilities of speaking to difficult circumstances, boredom and the tedium of waiting. Conversationally, time metaphors helped translate seemingly unthinkable scenarios during a liminal process (Van Gennep 1960). Temporal metaphors accounted for flexibility, lack of understanding and ambiguity in relation to the often dire circumstances of specific children like Gift, Themba, and Carlito. Through metaphorical framing of time, one can better understand the ways that metaphor reflected the jagged realities of tedium and life for many BCH children, as well as the nurses who cared for them.

‘Betwixt and Between’

In his seminal studies on liminality and rites of passage, Van Gennep suggested ‘the life of an individual in any society is a series of passages from one age to another and from one occupation to another’ (1960:3). He considered typical rites to include life events such as: pregnancy, birth, marriage, death, baptisms, bar mitzvahs etc. (Van Gennep 1960). Van Gennep divided rites of passage into three distinct stages: *preliminal rites* (rites of separation), *liminal rites* (rites of transition) and *postliminal rites* (rites of reincorporation). ‘A rite of passage begins by ‘severing connection’ with a previous social state or position, followed by an ambiguous time where individuals find themselves ‘in-between’ social positions, and ends with ‘re-entry’ or ‘rebirth’ into a new social position (Hockey 2002 ci Blows et al 2012:2156). Turner (1967, 1969) pointed out that rites of passage are not restricted to ‘ascribed social statuses’ like birth, marriage and death, rather they can apply to one’s entry into a ‘new

achieved status', or membership into a certain group (Turner 1967:95). Turner focused on the sociocultural aspects of the liminal period, and theorised that liminality or transitional periods were hard to identify with culturally recognised states like being married. Rather, liminal states are 'interstructural' meaning they evade such classifications via socially and culturally acknowledged structures. Turner explained that liminal actors are 'invisible – they are no longer classified and not yet classified' (1967:97). Liminal actors are often described as peripheral, marginal or on the edges of society. Upon admission to BCH, the liminal state commenced; most paediatric patients were discharged after a six month period of treatment, thus ending this liminal phase. This chapter looks at those who were not discharged in this way.

Recently, liminality has served as a framework for understanding patient's subjective understandings of time, especially in relation to cancer diagnosis, treatment and ultimately survivorship⁹⁷. In no way do I assume linkages between TB and cancer, as every experience of a chronic or severe disease is unique and contextually contingent. However, there are aspects of liminality which apply to the experiences and the currency of time I argue here. Molzahn et al (2008) offered a specific reading of liminality which relates to illness and disruption. They suggested that 'liminality refers to the ambiguous experience of one's life story being disrupted through illness' Molzahn et al. (2008:15). The ambiguity, the uncertainty and the 'not knowing' of patient's experiences maps onto the 'betwixt and between the normal, day to day cultural and social states' Turner so aptly described (1979:94).

Lakoff and Johnson's (1980) seminal work on metaphor, although now over thirty years old, resonates exponentially for the following chapter. The authors theorised that people often employ metaphorical language to talk about abstract concepts, but also extend that theory further to describe metaphor as a way of interacting with the world. As human beings, we employ conceptual systems which help structure our world; however, we are rarely cognisant of those systems, or the ways we go about *doing* this. Linguistic artifacts-like metaphor- help structure, make sense of, or clarify what one desires to convey. At their most basic function metaphors make complex concepts, emotions or experiences more accessible. Susan Sontag

⁹⁷ See Little et al. (1998), Martin-McDonald and Biernoff (2002), Thompson (2007), Molzahn et al. (2008), Blows et al (2012)

has criticised metaphor use in relation to illness, but refused to acknowledge the practical and often taken-for-granted utility metaphorical language enables. She stated:

“Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” (Sontag 1978:3)

Here I link Sontag’s ‘kingdoms’ with the rites of passage framework to locate the abstract into a physical space (Van Gennep 1960). Sontag’s metaphorical ‘kingdoms’ represented two different forms of citizenship nested in two different spaces. She made this distinction very discrete. When read with Van Gennep (1960) and Turner’s framework (1967, 1969), the distinction is less blatant and more ambiguous. Where does one kingdom begin and the other end? Liminality can be a metaphor to describe ambiguity, chaos, purgatory. The burden of time incurred through waiting is vividly described by art therapist, academic and cancer survivor Caryl Sibbet (2004). Sibbet worked with cancer patients facilitating art therapy sessions, and was also diagnosed with cancer. As a cancer patient and academic, she shared personal and professional likenesses to Sontag; however she embraced liminality as metaphor in order to interpret (and make sense of) her breast cancer. She explained, ‘There were seemingly endless hours of waiting – waiting for appointments, waiting for scan results, waiting for the sword to fall, or not...’ (2004:2). Sibbet also explained that liminality served as a productive metaphor with which to speak about thresholds: between life and death, a cure, or survivorship (2004). Liminality has also been described as a “fructile chaos, a fertile nothingness, a storehouse of possibilities...a gestation process...” (Turner 1986 ci in Sibbet 2004:6).

Recalling Sontag’s (1978, 1991) criticisms of metaphor in the introductory chapter, this section reaffirms the *practical use* of metaphor in language. Nurses, children and doctors employed time-related metaphors and temporal references out of pragmatism, not frivolity or superficial reductionism. Metaphor use was a way to express difficult situations which were seemingly beyond control. As explained in chapter 3, biomedical explanations of duress and trauma, ailing bodies and imperfect medicines often fail or cannot account for confusion, bafflement or ‘not knowing’. It was this very ‘not knowing’ that lent itself to the concept of *time as a commodity or a resource*: one either possessed or did not.

Thinking about time as a currency – something that can be lost or gained, spent or saved – directly related to how individuals conceived of burden. Time was used as a device with which to understand how burden was verbalised, conceptualised and choreographed through different experiences in Ward 3. Time was a burden to many BCH patients, and some of their guardians. I argue that whilst time *can* be a burden, it is during a child's treatment stay at BCH that possibilities for new forms of home are made; especially when the treatment period is extended. Most of the Ward 3 patients never referred to BCH as a 'home' in the traditional sense, while other children faced the prospect they would never return to their outside homes due to dire circumstances beyond their control. It was these children who created transitional homes in liminal spaces *despite* the warnings that BCH was 'not a home' from some teachers and nurses. These circumstances, accompanied by the state of social development and social services in South Africa, resist a linear, ordered sequencing of time. Although an 'objective' temporal model of time is utilised in governing all aspects of treatment at BCH, the chaos and uncertainty of the immediate present (and future) resisted such temporal anchoring.

Defining Burden/Disruptive Burdens

As discussed in previous chapters, there are various consequences that accompany a positive TB diagnosis for both patients and their families. Admission to BCH creates an extra dimension of burden, in unexpected ways for both staff, children and their families. In her research on TB and mothering, Ziyanda Ndzendze stated that TB is '...something that burdens and also unburdens the mother and the whole family simultaneously' (2012:19). Ndzendze's focus was the disruption TB caused a mother and the family in terms of care, and the financial alleviation provided by the government disability grant. My research shifts the focus to patients who are minors and are placed in the care of BCH by their parents or guardians. The absence of the child at home, while a disruptive and unsettling occurrence, does not necessarily bear the same weight as an ill adult unable to work. Ndzendze added that oftentimes mothers would feel additional guilt or emotional burden after having to 'outsource' caretaking responsibilities to immediate or extended family members because of their TB (2012). In contrast to the 'outsourcing of mothering' Ndzendze described, sick children at BCH are taken out of the care of their families or guardians *entirely* and *all* care is outsourced to the BCH staff.

In stark contrast to a mere 'disruption', TB diagnosis, and subsequent treatment at BCH can be life-changing processes. As Stacey and Bryson argue in relation to critical illness, 'Time

becomes newly relational, undoing the neat sequential flow of past present and future' (2012:5). Burdening and unburdening emerged in unexpected ways via different narratives provided by children, their parents and BCH staff. From the homes of people I visited upon discharge to parents coming to visit their children, time-related metaphors rendered new perspectives on how 'burden' was conceptualised and how the 'unburdening process' occurred. Those affected by TB are burdened and unburdened simultaneously, whether they be patients, parents, guardians or BCH staff. In contrast to Ndzendze's work (2012), burden was measured through time and how it was lost, wasted, spent, and generally consumed. Some parents regularly visited BCH, whilst other parents or carers did not. To many, the trip to the hospital was a financial burden, despite the TB care grant all families received from the government. Others could not afford to take time away from work, or the long distance commute from outlying areas. As Lakoff and Johnson theorised, time as money, a limited resource or as a valuable commodity are all metaphorical concepts (1980:457). Time is typically associated in Western cultures as something quantifiable, but by no means exists through the same conceptualisations elsewhere in the world. However, my data evidenced time at Brooklyn as limited and valuable, burdensome and tedious.

As Ndzendze (2012) found in her work, the TB care grant⁹⁸ assisted with helping to *unburden* families financially. Hypothetically, the grant money was meant to supplement the costs of caring for a sick child, in addition to provision of extra income for food, and transportation costs to visit the child. The majority of the families used these monies to the advantage of their child. They were able to visit, provide pocket money to be spent at the tuk shop and sometimes extra food. On visiting weekends, the extra income allowed a family to provide food and transport to their child to and from BCH. These families, according to the teachers, nurses and doctors, were the 'good families'. They helped ensure their children a shortened (or at very minimum a 6 month 'normal') stay through their persistence and support.

The following sections do not discuss at length these normative assessments of 'good' families or the values associated with that labelling. Rather, I discuss the looping, the layering and ultimately the liminality of time. A type of temporal resistance caused by human error and inefficient bureaucracies produced a specific liminal existence for Gift, Carlito and Themba.

⁹⁸ There are seven different grants recognized in South Africa and provided by the government. They range in type and monetary value from ZAR 240-ZAR1, 038. See for more information: http://www.tac.org.za/sites/default/files/equal_treatment/2012/ET27English.pdf

BCH was much more than a health care facility in this sense; it was a half-way house, an intermediary place to live before the ‘next step’ in their placement process. For these young boys, their experiences at BCH could *only* be read through time. They were the longest-stay children during the research, and each boy had lived at BCH for almost a year. Although the tangle of bureaucratic processes necessary to their discharge from BCH was time-dependent, their individual temporal experiences suggested otherwise. For them, time stood still in many ways: resistant to any forward motion, or progress with their social service placements.

Themba: Gone in No Time

This chapter commences with an analysis of burdens verbalised by Ward 3 children. Interviews with nurses and teachers provide different forms of burden they experienced in their daily, professional lives at BCH. All forms of burden were galvanised through temporal experience and the value individuals assigned to time. In this sense, I build upon Lakoff and Johnson’s work on metaphors (1980) because time was a resource which undergirded experiences of burden, and makes the distinction between ‘larger’ and ‘smaller’ burdens. Lastly, I discuss the notion of ‘work as burden’. While many nurses described working with Ward 3 children as something they reviled, caring for them was within their job description, and was at the core of their profession. Unlike the type of care discussed in chapter 5, care here is reformulated as burden and burden is expressed through time.

During Themba’s stay at BCH his mother passed away from TB. Although his extended family came to fetch him for the funeral, there was no family who wanted to raise him. Unlike Carlito or Gift, Themba was placed very quickly. He was present at BCH one day, and was gone the next. There were no goodbyes or teary farewells. I attempted on a number of occasions to correspond with the respite center in Khayelitsha where he had been placed, with no success. Some weeks after his departure I received an email response stating that they ‘do not have a child by that name’. Themba’s TB treatment was finished, unlike Gift. Dr. Early explained that BCH would continue to keep track of Gift as long as he was on his treatment. After that, they ‘let go’. In Themba’s situation, TB was the vector for unburdening the family. When there was no one outside of BCH to care for a child, the responsibility devolved to BCH.

In this sense, paediatric TB continues to be a ‘charitable’ disease. The links between the Australian preventoriums (Grose 2011) mentioned in the introduction, and the charity-driven institutions mentioned in chapter 4 span more than a century. One witnesses a web of patterns

which transcend time and geographical space; what was once old, is new again, the temporal cycle renews itself. TB diagnosis and treatment at BCH unburdened a family in many ways, but burdened the child immeasurably. The child bore a multi-meaning burden; one of sickness and isolation, and in many cases growing up in the care of others without biological relation. The burden had shifted institutionally without the presence of family willing to come forward to care for him.

Gift: Time Standing Still/ 'Stuck' in Time

‘Social development in South Africa is a bad place...it’s extremely bureaucratic. It takes a long time for anyone to end up where they should be.’ - Victoria, BCH social worker

At the beginning of September 2012 I wrote:

Two weeks ago Gift was meant to go home and Theresa said there was no chance of that. She tried to verify multiple times with Gift and the nursing staff, but and he kept insisting that it was so. Theresa phoned Khaya and then phoned Dr. Early. Back and forth and forth and back – it resulted in Early getting very upset. Theresa explained that the ‘child prepares for the date’ when it comes to discharge. ‘They know the date and it’s disastrous if the date changes for whatever reason.’ Gift’s father’s sister is meant to be coming from Kimberly to fetch him because mom is dead and father doesn’t care. Granny drinks his grant money and her boyfriend is abusive.

Gift continues to cry all of the time. You can’t really interact with him he’s so fragile...I cannot identify what he must or may be going through. It tears me apart to see him so upset. But what can I do and legitimately what can I say to make him feel better? I can’t say anything other than how sorry I am. It’s an emotional abyss and a conversational dead-end. We sit in silence for what feels like hours...but really it was just 30 minutes...it’s still a long time to stare at a corridor hall while sitting on the ground. [Field notes]

This excerpt from my field notes is described by Sibbet (2004:5) as ‘secondary liminality’, or ‘vicarious exposure to the liminality of those in liminal situations’. My understanding and ability to keep track of time was defied by the amount of empathy and ultimately helplessness I experienced on his behalf.

Gift’s situation worsened over the coming weeks. His grandmother had come to visit him, but she was visibly inebriated. His BCH social worker, Khaya, had sent the paperwork to remove

Gift from his grandmother's care to the social worker 'on the outside'. The outside social worker paid a home visit to inspect the conditions of his grandmother's home. In her report she stated that she feared for Gift's life if he was placed in his grandmother's care. During the visit, Gift's grandmother and her boyfriend were intoxicated by 9:00am, and the conditions were described as 'terrible'. There was no food on the premises and the house was described as 'filthy'. The final recommendation stipulated Gift's removal from his grandmother's custody. I spoke to Khaya about feeling helpless and she explained:

'Kate, it's a terrible situation that one. I know you want to help...maybe speak to these people. But there's no sense in it. If you go to that place, it will break you. It is just too sad to see them wasting their lives. The time this will take...yoh. It's too long. I am asking you please to not go there (to the grandmother's home), it is terrible.'

Khaya's reflections on time *wasted*, reflects the devastation alcohol abuse takes on a human life, and time wasted when not living a healthier lifestyle. She made another reference to the amount of time it will take to find Gift a place of safety. She knew it was going to be a long, bureaucratic process, however, no one could quantify the amount of time.

One afternoon I spoke with Nurses Dee and Lily. Nurse Dee worked relief shifts in Ward 3 when there was need. The conversation shifted to Gift. I remarked on the hopelessness of the situation and my inability to productively sympathise with him.

Lily responded, 'It's none of my business, but you can't get involved in these things, Kate. You'll die being too involved Kate. You mustn't do so, ok *meisie* (girl)?'

K: 'Do you think I'm too involved?'

D: 'Yes my girl. You spend too much time worrying about them. It will be the end of you...'

L: 'Definitely meisie. They aren't your children! You mustn't my dear, no, no. This Gift, oh it is so sad!'

D: 'Gift is a very sensitive boy. Very sensitive. It's just so sad. It really is...but *this is the life someone is given*. What can you do?'

For Dee, spending 'too much time' linked to death – time 'costs' – led to an inevitable, mortal end. Again, there was no solution or advice given, because this was, as she said, the life Gift was 'given'. For Dee, this was a preordained destiny, there was no way to alter or mediate the course of unfolding events. The correlation to Khaya's comment about the emotional and

psychological toll she feared I would experience at Gift's grandmother's home added to the feeling that time was the ultimate cost someone could 'pay', the ultimate burden, a deathly end.

During Khaya's leave, the same social worker did not submit the paperwork to social services, nor did she do anything to expedite Gift's case. Khaya returned from leave to discover that his case was 'not moving'. Other frustrations emerged when Dr. Early and Theresa had an argument because the discharge date had been moved around too many times and everyone was confused as to *when* Gift was actually meant to leave BCH, or *where* he was going to live.

Gift's situation represented a warped temporality, a liminal space (Van Gennep 1960). There were disagreements amongst staff, incompetent social workers, dire living circumstances and no *forward* progress. Time felt stagnant, agitated and backwards. Perhaps even more frustrating was that there were very few ways to productively discuss the circumstances with him. He already knew everything there was to know. There were no secrets, no white lies. He was 'stuck' in a tug of war ennui, a stifled, liminal space, a waiting room for the next step in the placement process. The general consensus among the teachers, nurses and Dr. Early was that all we needed to do was wait. *All we had was time*, and a lot of it.

Lakoff and Johnson explain that:

'The concepts that govern our thoughts are not just matters of intellect. They also govern our everyday functioning, down to the most mundane details. Our concepts structure what we perceive, how we get around in the world, and how we relate to other people. Our conceptual system thus plays a central role in defining our everyday realities. If we are right in suggesting that our conceptual system is largely metaphorical, then the way we think, what we experience and what we do every day is very much a matter of metaphor' (1980:454).

Teacher Candice described the complexity of Gift's situation in contrast to Carlito and Temba. 'The problem is that Gift knows. He knows the whole story...which makes it so much harder for him...this back and forth business, *so much time lost*.' Here, knowledge and transparency contributed to extra burden. Gift's knowledge about his family circumstances became a burden and paradoxically contributed to the murkiness of the future and a final destination determined by social services.

Gift explained:

‘I just want to go home, Kate. I’m sick of this. My medicine is right, I am right. I take it all the time. But where can I go? There’s no place to go, except here. I’m just sick of this place. When can I go? My discharge was a long time ago, yoh. How much more time now?’

A month later in October, new social workers arrived with Khaya. We returned from school and they were standing in the ward. Gift rushed to pack what few belongings were unpacked from the side locker. Everything happened quickly. It was as if the moment collapsed on itself. Theresa, Candice and Grace were not present to perform the normal good bye ceremony. I helped initiate it, and we circled around Gift, hand in hand. Afterwards, Dr. Early approached him and encouraged him to stay in school as much, and as long, as possible.

‘Gift, don’t be in a rush to leave or grow up too fast. Please take your pills’, she explained. And then he was gone.

I wrote about his departure:

When the state social workers came in with Khaya, everything was really rushed, everything was speeding up, and I just wanted the moment to stop. We all said goodbye but then it was awkward because there was a stack of paper work to complete. And so they sat on the stoep, and he sat with them, suddenly isolated from our group of Ward 3 children. I didn’t understand what was going on, it was complete chaos. Nurses packing bags and bags of medicine, children in various stages of screaming, fighting, crying and playing. And in this whirlpool of activity I just watched Gift sit still at this table of adults. A weakened smile on his face, isiXhosa only scarcely audible over Takalani Sesame⁹⁹ playing on the television in the next room. [Field notes]

On the seventh of October I wrote the following after I received a phone call from Gift:

I was under the assumption that because Gift’s grandmother drinks a lot and his eldest sister didn’t want him, he would be going straight for placement with a house of safety. You can imagine how surprised I was when he called...he sounded so happy. Gift explained he was with his grandmother and aunty. I asked him why he wasn’t in the respite centre, and he said he

⁹⁹ The South African version of the American children’s show ‘Sesame Street’

was going to the home the following day. I told him to call if he ever needed anything. [Field notes]

One month later, Gift arrived back at BCH.

Carlito: Running Out of Time

If they have the right support they can go far...if they don't, there's little hope' - Dr. Early

In September, Carlito's social situation had shown no sign of improving. The nurses shared similar opinions on Carlito and his behaviour:

Nurse Jones explained, 'that one (Carlito) is just getting bigger and more naughty by the day. 'There's always trouble. When there's a child around, there's always trouble. What can you do Kate?'

Nurse Lily added, 'It's maybe the end of the road for him...he has to be placed soon'...'we must pray for that one Kate...he doesn't have much time.'

The idea that time was 'running out' resounded with the notion that Carlito could not be housed at BCH indefinitely, and the nurses were frustrated with his 'naughty' behaviour. He stole food, sweets and money, made racist remarks, and he picked fights with other children. And yet, similar to Gift, he had nowhere to go.

Daily, Carlito said how he was, 'going to a church and a new school (foster home)'. I wondered where this information came from, and asked Candice and Theresa.

Candice explained:

'So what we did with Carlito, is that we told him that his mum was getting a house (from the government), and that in the meantime, he would be staying at another house. We did the same thing with Themba. He was waiting for a family that never came. A father who who'd never been interested. So Grace told him that he's going to a new house....which he is...but he'll most likely never see his father again. And because his mum passed. Well, that's it really.' - Candice

Here, knowing *something*, whether it was true or not, served to assure the child that there was an 'end destination' in sight, a way out of liminality. Knowing *something* was better than *not knowing* at all. In Candice's opinion it helped '*pass the time*':

'It gives them something to look forward to. They're not stupid. They can put together the pieces. They know, Kate. But they can know later in life, once they're older, not

now. It can wait until they are able to understand everything. With time, they'll eventually understand all of this.'

In Candice's opinion, only time could reveal the magnitude of present difficulties. Neither she nor any of the teachers felt equipped to explain to Themba and Carlito the extent of their social circumstances and the degree of complexity. In contrast to Gift, time was a saviour and would act as a vehicle for further clarification. It was only with time that both boys would mature to the stage where they would understand the trauma of the past.

Days later, Carlito's stepfather's son, a teacher, spoke to Dr. Early and the Ward 3 nurses. He doubted that his father or Carlito's mother were capable of taking care of him, and he insisted that Carlito be taken in by social services. The next day Carlito's mother and her boyfriend arrived in Ward 3 where we sat on the stoep drawing with crayons. Nurse Lily surveyed the scene and whispered, 'Just watch them, and see what they do. They're only here for one thing...making a big show, just for the money'.

The following week, social services notified the Ward 3 nurses. They would come to fetch Carlito to bring him to a place of safety. Victoria's instructions on his file read: 'Absolutely, under no circumstances, allow his mother to take him off the premises of BCH'.

Victoria has been a social worker for 10 years, four of which were in Mitchell's Plain. She explained to me the differences between BCH and the 'outside':

'BCH is a slower pace, whereas being in 'the field' is quite fast. There is little face to face interaction but there is *a lot* of crisis management. You simply can't trust what you see here. People will come dressed up with all sorts of promises, but they won't spend time with their children. Perhaps they will come initially, but after that the visits thin out. And you can tell who are the good mothers, and the good families. They come on a regular basis. Others are just there to drink the grant money or use it to abuse drugs. That is the situation with Carlito. He's so young. In general, it's a sad state of affairs we see.'

Victoria's temporal model linked time spent and frequency of visits to the quality, or 'goodness', of the parent or family.¹⁰⁰ The less time spent or paid at BCH with the individual child, the more amoral the parent was perceived. Victoria was not alone in this opinion, and many staff members felt this way.

¹⁰⁰ See Marshak (2013) for moral dimensions of care.

Nurse Lily voiced her concern:

‘Yoh- Somebody needs to come and get that child. I truly don’t know what will happen to that one, but surely he cannot go back to his mother or that stepfather. The things he has seen, Kate. He has told me how his father is going to kill them. His father has a gun and gets very violent towards his mother. How he is beaten, how there’s no food and no money. You remember when he came here with those rotted teeth...terrible. He’s scared. And he tells me how they all sleep together...it’s just not right...and he’s at that age – he can still come right, with time – to learn right and wrong. But not with those two parents. It’s best that he’s taken. On my side – I feel like they must talk to them...the one learns from another one...if they can put him alone and get it into his head...but to be in the company of him – that boy has had a lot of missed opportunities and it shows. He’s a bit of a mess. And I’ve seen it too many times. But time for that one is running out I think.’

Again, Lily used the idea that time was ‘running out’ for Carlito, and it was a scarce commodity for him. Within Lily’s model of time, there is only a small window of opportunity where his social skills and behaviour could be altered or salvaged. Without that time, Carlito would become unsalvageable, amoral, or a lost cause. Her sentiments resonate with the moral panic discussed in chapter 4. In contrast to this, she also explained that time spent at BCH changes a child, sometimes for the worse.

‘Children come in – they’re quiet and they’re nice, they’re respectable – because they are scared. *Give them some time... a month or two.* They start changing. You have the good mothers come in saying ‘what has happened to my child?’ He wasn’t like this or that – and now – after this place? So it’s best – on his (Carlito’s) side – he must go to a private home, not just another place like this you see.’

On the Friday Carlito was meant to be taken away, I said my goodbye. The following Monday, he was still at BCH.

Carlito couldn’t leave. I had said goodbye to him the other day, only to find him back again the next. He was meant to go with a social worker to the Cedarburg for a placement – some 2-3 hours past Worcester...but the social worker could only fetch him on Monday, and hence the goodbye is lengthened. I don’t know what is going on, this is chaos. [Field notes]

Nurses: ‘You must take the time’

‘It’s hard to get nurses to want to come here. No one wants to work in this ward with these children.’ - Nurse Lily

‘These people shouldn’t make promises to their children. Meanwhile, there’s no food at home. There’s no clothes....maybe no water. It’s just not right. And where does that money go?’ - Nurse Jones

This section illustrates the sense of burden nurses felt working with the children of Ward 3 via the dichotomy of time ‘spent’ and time ‘wasted’. This terminology created an instant polarity between putting in ‘good’ time and having your time ‘taken’ from you by ‘unruly’ children. Nurses Jones and Lily were the permanent nurses in the Ward, and received little relief, save for holiday. In conversation with nurses especially, Ward 3 was not a ward anyone wanted to work within.

There is a growing body of literature which focuses on the experiences of nurses in paediatric care environments. Ford and Turner’s (2001) work was exceptional in this regard because it highlighted the frustrations in care experienced by nursing staff tending children with long term illness, and thus long term hospitalisation. Coyne’s work (1995) demonstrated that many nursing staff were uncertain about the levels of parental involvement when a child became hospitalised. Other studies demonstrate similar mixed feelings about the centeredness of the family in paediatric care. Surveys conducted by Seidl (1969), Johnson and Lindschaus (1996) illustrate that nurses in paediatric wards have different attitudes towards parental participation based on a variety of factors: level of education achieved, employment, or being parents themselves. Totka (1989) and Benner and Wrubel (1989) advocated for more research on nurses interpersonal relationships with families and patients through nurses’ varying experiences of nursing practices. These are ‘Stories Seldom Told’ according to Ford and Turner (2001).

The following discussions reveal the frustration, burden and minimal hope many nurses came to associate with Ward 3. Some, like Nurse Dee, had previously worked in Ward 3 and could ‘no longer cope’ with children and moved to an adult ward. Nurse Nadine was a ‘fill-in’ nurse when Jones or Lily went on holiday. Unlike the majority of the nurses I interviewed, she loved working in Ward 3, and loved the children. As previously mentioned, nurses often framed the ‘goodness’ of a family or a mother in terms of how much time was spent with their children in visits to BCH, thus echoing moralised sentiments; but here I tie time-related metaphors to a sense of individual burden, not morality.

Nurse Dee: ‘You just don’t have any more time’

Although Nurse Dee no longer worked in the paediatric wards, when she was on shift she spent her lunch breaks on the stoep with Jones, Lily and other staff members. Lunchtime was spent eating, sipping tea or coffee and catching up on the latest gossip circulating at the hospital. If I wasn’t in school with the children, I spent my lunch with the nurses on the stoep.

Nurse Dee explained to me the merits of BCH. She, like Nurse Jones, lived on BCH premises in the Nurses Hostel.

‘You know Kate, a traditional hospital is more hectic. It’s nice that it’s (BCH) not like that. I’m from Namaqualand, but I’ve been here at Brooklyn for 32 years, that’s a long time, hey? Nothing happens in Namaqualand. People are full of *stront* (shit/nonsense). I must stay here. It’s not medical things and surgical things. It’s nice. Now I’m of pensioner age, well, in two years or so. I want to stay here. If I don’t then I’m on my way back to Namaqualand, and how will I spend my time there? But I’d like to stay and clip the children’s nails for three hours a day. Volunteer or something like this...but for short amounts of time. I was in paed for 10 years or so? They shifted us, you see. Thank God. I started to get irritated with the children, I had no time. I did night duty too back then. It sometimes makes you a bit off.’

‘You just cannot deal with them any longer. You don’t have *any more time* for them and their antics. They can be full of nonsense at the night time, child!

Aunty Rimelda, one of the cleaners, chimed in, ‘Yes, but they must *do* something. I wash the floors three times a day...The linens get changed daily...they can do that. Make their beds nicely. Prevent the contamination. It’s not a holiday here, mos. They *must put in time*.’

Again, Dee’s model of time referenced the attitudes and behaviours of the children and the amount of time it took to mediate conflict or take disciplinary measures. The more the children ‘acted out’, the less time a nurse wanted to ‘deal with them’. With children like Carlito, the frustration was visible. Whereas Nurses Jones and Lily tried to be patient, sometimes they felt patience was impossible.

Taking the Time, Shouldering the Burden

For all of the time that many of the parents did not spend with their children, there were those who tried to reinforce positive time spent with the children, especially members of the nursing staff. Nurse Nadine was one such nurse. During the two weeks she filled in for Nurse Jones, we discussed the children at length. One evening she explained:

‘This is a tough business, and it’s not an easy job. But *you have to take the time*. It’s part of the job description. It’s what we are meant to do. There should be no questions about that one. Many nurses are here to collect a pay check. They think they put in the minimal amount of time, and then they can just get paid for that. It’s the extra time spent – going the extra mile for the children. They need that time. It’s valuable. Many of these ones (children) don’t have families who care enough to come in...Or they make up some excuse, because it is a burden to them. But this, this is our career, as nurses.’

In her temporal model, the burden many nurses feel in terms of time constraint is unfounded.

She explained:

‘I just don’t understand how a grown adult can be so *onbeskof*¹⁰¹ when the children misbehave. It’s completely unprofessional. They’re children, mos. If we can’t allow them the time and space to do that, how will they learn to grow up proper? Their parents won’t take the time to do so...which leaves it up to us. That’s how I see it, nuh? But still, you see Kate, I hear stories about other night nurses...becoming violent because they are *gatvol*¹⁰². Beating the children and saying ugly things to them. I tell my colleagues, they really need to make sure they don’t lay a hand to the children. They must be shown love, and you must take the time for these children. I remind them, these are not our children. It’s the *least* we can do. Dr. Early is such a good example. She treats these kids as her own. We must do the same. If we don’t? How will they (children) ever trust anyone again?’

To Nadine, the time spent was inherent in the capacity to care and do one’s job fully and correctly. The amount of time spent with various children would only aid in their development as adolescents and eventually adults. She was critical of other staff who lacked the patience and perceived ‘extra time spent’ as a burden and outside of their job description. In her opinion, there was ‘no place for people like that in a hospital’. Her allusion to Dr. Early as a mentor and an example of care was echoed by every nurse, cleaner and teacher I spoke with.

In an interview with Dr. Early, she shared her opinions on time and staffing allocation. Her opinion differed slightly from other staff I spoke with, in that she feared that older nurses were hesitant to work in ‘potentially infectious environments’.

‘Maybe as nursing staff get older, are less creative and energetic, the children seem more draining? Just a thought, because our staff are definitely aging and less younger ones (nurses) don’t seem to want to work in a potentially infectious environment. With

¹⁰¹ Afrikaans: rude

¹⁰² Afrikaans: Fed-up, frustrated

the higher load of MDR and all the tests accompanying, I myself have spent less time just 'playing' with the children in Ward 3...'

Grace reiterated the same sentiments about Dr. Early.

G: 'We've got a very sweet doctor. She is amazing. She does all that she can to make her children happy. She treats them as I do, like her own children, she spends time with them. There are nurses that are really kind, they make it like home here. There are others to whom work is work. It differs. Sometimes I get mad with the nurses and the cleaners. I get really mad. But then when I come to the sense that we're not the same...how can they be like me? I calm down then. There are some situations where I will ask someone why are you treating a child like this or doing this to a specific child...and this is when we hear stories about nurses being racists, or verbally aggressive, or violent in a physical way....stigmatising kids for a situation out of their control...it makes no sense to me. The children are happy to open up to me and to others, like yourself...and it's easier to do that then open up to the doctor or the nurse or whoever...for whatever reason. They tell me things and I freak out. I go and ask why does this happen...and I confront the people responsible and I ask them – what is wrong with you? How can you treat a child like this? They are trusted in your care.'

G: 'Yeah – it's not instantly. The old group (patient group 1) – they were hard kids...this group now (patient group 2) – it's smoother. It's sad. This is a place where parents are trusting the state to take care of their own children. If they can't trust us to do that – how will these kids every transition smoothly back to their old life – where there may not be a lot of trust either? Who will they trust?'

G: 'To see the children not happy to be where they are supposed to be happy. Kate, this is like home. No one can tell me that 6 months away from everything that is familiar is a holiday. It's not. It's a long time – whether you are a child or an adult. And it can be a longer hospital stay than that too...you have to be feeling like this is home. Its home, in a hospital. They're not here to take treatment and go and take treatment and come back. It supposed to be like home. The people who work here have to create that feeling of home. It is a home within the hospital Kate. More than swearing and being a bully or telling them what they don't want or need to hear with their little ears...'

K: 'Yeah...I agree. I can't not love and hug and kiss them.'

G: 'And why not? There's no harm. We don't wear masks and yet you hear don't touch them, don't be too intimate. Why not? They need love to heal, and love is free. They need it.'

For Grace, like Nurse Nadine, time was conceived of in a positive nurturing way. It was a characteristic element necessary to the profession and the unique circumstances of the paediatric ward.

Back In Time

Many nurses employed time references to draw comparisons between children both past and present. Their descriptions of children ‘in the old days’ heralded back to a golden age of the institution that brought with it moral values and innocence, a time when life was ‘less complicated’ although the paediatric patients were ‘far more sick’. These retellings of time presented children as innocent and untainted by the ills of society, as discussed in chapters 2 and 3. Conversational time travelling with BCH staff collapsed decades of experiences at BCH and provided yet another dimension of analysis and temporal topography.

As Nurse Lily explained:

‘I’m here for a very long time – over thirty years here at Brooklyn. I worked in the big people wards, but I came here working in Ward B – the baby ward – and then the big wards and they brought me back to Ward B. In the end they tried to teach me the medicine trolley and from there they knew I could admit the babies, administer medicines...they knew I had the skills to do this job.

K: ‘Do you think it takes a different type of nurse to work with the paediatric patients here?’

L: ‘Exactly it does. If you work with children – you must know...you must come down to their level. You must play with them, you must hug them...you must be there, to spend time with them. You know mos in the big wards they just drink and maybe care for their nails if they are too weak...but with kids? We’re washing them, you must do everything for them. There is a difference in nursing here versus adults. Children do fight and come complain – all these stuffs...you must be like a child if you work with kids...you mustn’t think ‘I’m a nurse and I’m just here to give medicines and drink your pills and finish and klar!’...no no no...You mustn’t be like a professional – you must be like them...and they will fight and mess and complain. In the big wards there’s no complaining every five minutes or messing...with the children it will happen. From my side, I love children. In the olden days here – we had so much fun it was beautiful...it’s not everyone who can work with children...it takes a special type of person truly.’

K: ‘How so?’

L: ‘...but it’s hard to get nurses to want to come here. No one wants to work in this ward with these children. It’s not nice....that poor child (Gift). It’s not nice to be discharged just to come back here after 2 to 3 months...I mean he was gone for a month – not a lot of time, but still...no, not nice at all...’

L: ‘It’s difficult...They didn’t choose this life. It’s not their fault – and yet – here they are. I take the child... I talk to them...they must learn...you have to change from the inside out. And if your parents don’t look out for you and care for you...there is a way out. They must talk if

they are unhappy. You know what these types of people do...They bring the child here and they say – right – here you are, here is my child. They are after the money that they think is theirs – for the grant. That money is meant to be used for transport to visit – as food for when they have the child at home. Not for them to drink...if you're a drunkie¹⁰³ - or to blow on drugs, as many do...To that I just say Fine. I'll take this child, I'll care for it, and I'll send you to the social worker. People are motivated by the money – they get it – they drink it – and it's gone. They hang on for that and put on a good show sometimes too. But otherwise – they'd be out of the picture. And they can be written out of the picture too don't forget. The mothers to get pushed out if they are using (drugs)...you can call and call a cell phone contact number the parents give – and not receive an answer...then all you need to do is call the child and they'll tell you what mummy or daddy is up to...drinking or tikking.¹⁰⁴ It all takes time in the end.'

K: 'Do you think that children change dramatically here during their stay?'

L: 'It's prison mentality...talk to the adults. It's a prison to them, they're all doing time...some of these children though...I spoke to one mum – and you know who I'm speaking about here...she said her son can now do all of these things he couldn't do before – very sufficient now. He was making his bed...he knows how to wash his hands and care for himself. Some of them become self-reliant during their time here. Some change for the better and some for the worse...it is a fine line. Some become so rebellious and rude...maybe it's their way to oppose the pills, the regimes, and the routines we rely on...I don't know. If the child was here –there's a huge difference. We try by all means to make sure they come out right – if they were naughty before or onbeskof – we try to give them those lessons...'

Time Standing Still

This chapter closes with a conversation between Nurse Dee and myself. One of the children's parents had just passed away in the women's MDR ward. Ward 3 was silent, the children were at school. Nurse Dee looked exhausted. We sat on the stoep in silence, punctuated by slow sips of tea. Slowly, she proceeded to express her frustrations, sadness and wondered out loud how she was going to break the news to the five year old girl.

'You know Kate...There's no counsellors here for us, there used to be someone though. We speak to each other. You get used to the patients. Sometimes they come back, and you see the same patients...if they have defaulted, or become reinfected. They don't understand...or they do, and they don't care. They get nice things here...hot water, biscuits, hot food, shelter and clothes. They come back and there's always a story. Maybe outside they don't have food. Some people live off the government grant. They

¹⁰³ Alcoholic

¹⁰⁴ A tik user

just eat the government. They need to eat their pills. Drink them up. Some people only live off the grant – how can they survive on that? It's the same thing, over and over. Time stands still in that way...And with this woman's death...she has a child. How will we explain this?'

Her eyes focused on a spot beyond the gates of the ward, beyond the grassy expanse of the BCH grounds. She continued to describe the emotional trauma nurses experienced working at the hospital. In comparison to the past when 'there was so much death', the situation had changed at BCH. 'For some reason it's not like that anymore you know...except a few weeks back...we had something like 8 patients die over a few days...so sad. I suppose they think that because we're nurses we just get used to it over time... like it's part of the job.'

'Get used to what exactly? The everyday trauma and sadness?' I asked.

Dee responded slowly, 'Of course, yes, that too...but what I meant was death. You don't get used to death. Death is awful.'

The liminal space at BCH presented staff and children with different burdens and challenges. Time, TB, and arduous social circumstances were often evasive, not fixed in the ways fashioned by biomedical ideals and process. The ways to 'speak to the unspeakable' took on different time-related metaphors that either expressed time as a currency, or a burden within the hospital space. Time was valuable, and value was understood through the experience of illness and treatment at the hospital. Contrary to Sontag's criticisms of metaphor (1978, 1991), Lakoff and Johnson (1980) have posited the praxis behind metaphor use, the utility when faced with the jagged realities of every day, and often 'mundane', life. I hesitate to categorise deeply unsettling circumstances like those of Gift, Carlito and Themba 'mundane'. Rather, as with most of my experiences at BCH, I was witness to ordinary people grappling with extraordinary conditions daily.

To wrestle with uncertainty, desire, the unspeakable or risk, time and time-related metaphors were used as conversational coping strategies. Time appeared as a resource, a commodity, something valued or something wasted. As evidenced through the stories of Themba, Carlito and Gift, temporality was warped, stuck, and often without the buttressing of linearity. The social experience of TB confronts and refuses to exist strictly within a biomedical conception of temporality. Again, the 'hospital time' reinforced through pill-taking routines, daily schedules and ward rounds in chapter 3 stand in stark contrast to the types of time discussed in this chapter. This is a messy sort of time, one which can only be spoken of with abstract

reference because it evades logical description, transcending the structure and shape dictated by clocks and calendars. A temporal space which does not conform to a sequential index; neat and orderly.

On this note, Dee's thoughts illustrated yet another dimension of time at BCH: one that was related to death. Death at BCH was timeless. It was an inevitable end for those who did not respond to treatment, or 'defaulted', only to come back to BCH to commence treatment all over again, and to 'do their time'. According to nurses, squandering time at BCH resulted in mortality. There would be no postliminal phase for patients who did this, no reintegration back into society on 'the outside' (Van Gennep 1960). For these patients, their time was up.

After TB: The World Outside

‘There are big challenges ahead for most of these children. Big challenges.’ - Nurse Lily

More than a decade ago, Paul Farmer lamented how TB was the ‘forgotten plague’ (Farmer 2000:185). Since that time, there has been a surge in TB funding, research and TB control programmes, as well as the number of people affected by the disease globally. Medical anthropologists have heeded Farmer’s call, and the upswing in Tuberculosis- related research has been phenomenal. Notably, the work of Koch (2011, 2013) in post-Soviet Georgia and Harper (2005, 2006, 2013) in Nepal and India demonstrate the work of medical anthropologists engaging local actors, large transnational TB control programs, pharmaceutical companies and public health organisations. However, there remains an absence of ethnography with paediatric TB in-patients, and the work presented here has aimed at filling this specific scholarly niche. Hospital ethnographies provide vital perspectives on institutional living. How paediatric patients perceive and ultimately experience TB can help frame and hopefully reimagine the conditions with which young people at the BCH experience their treatment.

Anthropology is replete with philosophical conflicts of representation and value, and this work is no different. It is, admittedly, a partial and imperfect offering. The imperatives, the challenges and the stakes are high when one endeavours to interpret the lives and experiences of those we work with. Those whose narratives I have been witness to remain here, crystallised in words and sentences and paragraphs. This too presents an illusion of finitude. What must be recognised here, in an attempt to conclude, is that there is (of course) life beyond the page and the print.

Overview

The introduction to this thesis surveyed the social, historical, political, biological and epidemiological terrain of TB in different parts of the world. South Africa, as a geographic locus of disease, has not received the same scholarly attention as other areas of incidence, primarily Europe, North America and South America. The works of Packard (1989), Coovadia and Benatar (1991) and Fassin (2007) are notable exceptions for South African scholarship. TB engages scholarly attention in a way no other infectious epidemic disease can or (perhaps) ever will. Given its extended engagement with human populations throughout time, continued TB prevalence and incidence merits continued consideration microscopically in local contexts

and within the global health arena. Figurations of TB are evident in the ways epidemiologists, historians, writers and physicians have approached it over time. . TB, as a disease, has captured the imagination of humanity, oftentimes to the detriment of those living (and dying) from it. The metaphors accompanying imaginative depictions too left their mark and, as theorised by Sontag (1978), at the expense of TB sufferers. But, to cast away metaphor and strip the disease of its social translations forecloses upon the ways social realms make sense of and interpret disease and those who are living with and being treated for them.

The Limits of Mutuality

Chapter 2 called for a reconsideration of the language employed by childhood theorists when speaking about research with children (Hunleth 2011). The chapter also discussed the ways in which language necessarily influences the methodologies child scholars use and how those methods are linguistically (and descriptively) packaged for consumption: in the academy and beyond. ‘Child-centred’, ‘child-driven’ and ‘child-led’ are perhaps misleading or inappropriate terms given my ethnographic experiences in a paediatric ward. The language we employ as anthropologists must reflect the realities of those we work with and the methods which are most efficient, productive and insightful: for us, as well as our collaborators. Positioning children as inherently vulnerable and innocent pigeon holes them into a corner of victimhood gilded by moral economy. Anthropology and those who practice ethically sound ethnographic research must be accountable for the language they use. When minors are placed in the care of a government facility, there is little room for agentic action; their day to day lives are governed by biomedical ritual and routine.

‘Agency’ too merits an ethnographic ‘recall’. Child anthropologist David Lancy (2008, 2012) in particular has questioned what he perceives as the cavalier use of the term. He rightly points out that many theorists use the term child’s ‘agency’ without necessarily excavating its meaning, how agency manifests itself, or how it is regulated. My data suggested that agency is severely inhibited when working with child patients in Ward 3. This finding proposes that further critical research around children’s agency is warranted, if not imperative. I do not mean to suggest that children’s agency does not exist, nor that it is unworthy of investigation; rather, I argue that children’s agency is thoroughly constrained by social, political and economic constraints. If agency is not freely available to all, as other studies proclaim, then why represent it as such?

This chapter reinforced the notion that careful ethical considerations strengthen fieldwork that is mutually beneficial to both researcher and participants. Too often academic literature focusing on methodologies ‘in the field’ fails to take inventory of the methods that are *less* productive. Methods like these are edited out, discarded and never to be returned to again. Ward 3 children were vocal and critical of methodologies they were more (or less) interested in. They clearly articulated which activities they did (or did not) wish to participate in. There was very little ‘guess-work’ involved. It was in this way that methodological mutuality came to the fore, through active (dis)engagement on their behalf (Pina-Cabral 2013). The limits of mutuality here were a fundamental component in adjusting to working with children who *looked well*, but were often very ill. As a researcher who works with those who have HIV, TB or both simultaneously, fieldwork is often quite challenging. Admittedly I do not, nor can I ever, *truly conceive* the difficulties one faces within a uniquely individual experience of illness. To quote my PhD supervisor Dr. Susan Levine, ‘Anthropology is a queer kind of calling’ (2012:55). I tried to orient myself in relation to those I worked with, and I hope, as Levine cautioned (*ibid*), I have not violently disfigured their narratives in my translation thereof.

Reading Bodies, Seeing Signs

Chapter 3 traced the biomedical rituals and routines children were indoctrinated into as they were admitted to BCH. Doctor and patient narratives provided rich evidence of the complexity of pharmacopeia and the overwhelming presence of technologies in the lives of children. Biomedicine requires adherence to certain principles and timeous responses, whereby a practitioner can optimally treat their patients. This, of course, is the sanitised account of what Biomedicine as a Culture *does*. It is, for practical purposes, idealised and fails to translate into the lived substance of illness at BCH. Improvisation of medicine (Livingston 2013) and phronesis (Human 2012) convey the merits of intuition through a physician’s eyes, to the betterment of their patients. Inadequate health infrastructure, sluggish bureaucracies and human error created a mine field of concern for BCH medical staff. Doctors articulated their concerns and quickly, concern morphed into momentary conundrum which was met by action, pragmatism and trust in one’s medical abilities and knowledge. Diagnostic technologies and more appropriate drugs are ‘in the pipeline’ for children afflicted with different types of TB, but for now, patients, their families and loved ones wait, and put faith in those who read children’s bodies intuitively.

Children laboured daily with mounds of kaleidoscope-coloured pills of various shapes and sizes. X-rays, audiology tests, the ‘vampire’ and a host of other regulatory tests, measured, calibrated, surveilled and ultimately helped determine *forward progress*. Discharge dates were the destination point every child hoped to achieve through their consumptive labour of pill drinking and x-ray taking. Many children considered their only job (and most important role) at BCH was to get better.

The figurations of the child from ‘vulnerable’ to ‘dependent’ was read through biomedical rituals which sought to contribute to the project of making a responsible child patient. This ‘responsibilization’ has been examined thoroughly by Robbins (2006). Teachers considered children to be role models to adult patients who also struggled with adherence to pill regimes.

Hospital Schools

Chapter 4, *Pedagogy on the Fringe*, figured the children at BCH as both students and patients. Learning accompanied healing, and the continuity created by the school was an important aspect of the children’s assimilation to a ‘normalised’ routine (Schlozman 2002). Whereas academic engagement was encouraged by dedicated teachers, the school healed student patients differently than the ward or doctors could. There is a long history of charity driven organisations taking special interest in the health of children and youth (Rankin 1993, McGinnity et al 2004). It is perhaps not a surprise that many of these organisations initially originated from faith-based organisations and structures. Africa in particular is replete with colonial missionary medicine accompanied by basic education provision (Vaughan 1991, Good 2004). It is here that one witnesses the confluence of religion and health, school and hospital.

Teachers explained to me how the school was not a school, it was a hospital first and foremost. The Brooklyn school was not registered, and many of the obstacles teachers encountered daily were related to the lack of recognition from the School Board, Department of Basic Education and other institutional structures. This bureaucratic red tape was made more complicated by on the ground struggles to contact teachers, principals or to find a patient’s previous school in the first place. I was confounded time and again through their explanations, because it seemed to me that the school was an active site of emotional, spiritual and mental support for paediatric patients. Issues which were not visible or iterated in the ward came into view within the school setting. The school was a sanctuary, a place of mediation and a comfort.

Helping Hands

BCH was also characterised as a volunteer saturated space, and children's experiences with volunteers was racially coded and materially framed. Initially I had not considered the presence of the volunteers as anything more than temporary, but it was the children's observations about the volunteers that compelled me to include their ideas in this thesis. The Children were confused about the role of adults that to them had no identifiable form of employment at BCH, but had an abundance of time to spend with them. I realised that interactions between children and volunteers lent another dimension to the landscape of care at BCH.

Existing literature provides abundant definitions around voluntourism, volunteering (etc.), the basic formula remains the same: travel + volunteer work + an identified group of people in need of assistance. Volunteers involved in service-learning projects spent time with children and completed tasks they identified as pertinent to their CSL projects. Children, in volunteers' conceptions, were positioned as inherently 'in need', and volunteers were present to give their time. Children were constructed as a component in 'self-making' experiences for volunteers, as well as undeniable recipients of aid, of material and emotional support, and oftentimes, love. Despite my initial (and personal) scrutiny of 'volunteers in Africa', volunteers generally were much appreciated for 'being present' by other BCH staff, and sometimes the children. Although Teacher Theresa was initially sceptical of their participation in the school, inevitably she welcomed them into the school.

The essence of volunteering is partially philanthropic – one donates time and effort in a bid to assist or help someone else – but the volunteer also stands to gain something from the experience. As evidenced through their responses, the volunteers at BCH wanted to 'help', 'lend a helping hand' in the 'third world' 'for the benefit of the children'. Children (and what they desire) and the volunteers who aim to assist are fundamentally positioned in a way that goes unquestioned. The children require the benefit of volunteers who have resources (whether intellectual, physical or financial) to aid them *in whatever way possible*. Although volunteers seemed aware of stereotypical representations, despite this consciousness they replicated many of the stereotypes they themselves mentioned in interviews.

However, Sin's work (2009) with volunteers donating their time abroad suggests another dimension to the voluntourism literature provided (Patel 2003, 2007). Sin (2009) theorised volunteerism as a 'self-making' endeavour. This type of scholarship better addresses power

relations, privilege and notions of responsibility, altruism and ‘self’ in voluntourism literature and pursuits. Sin’s foregrounding the ‘self’ was a way to theoretically deconstruct motivations behind volunteering in a foreign context (2009). Volunteer experiences replicated this ‘self-making’, but also (to my surprise) did so in ways which were to the benefit of Ward 3 children.

Didier Fassin (2013) criticised the moral economy language around humanitarian interventions in Africa, specifically in South Africa, calling it the ‘humanitarian problematization of childhood’ in South Africa. As long as children are promoted as inherently innocent, humanitarian intervention efforts will continue to *speak for* children as perpetual victims. Fassin warns that the moral economy can serve to deconstruct and illuminate the illusory veneer glossing much of humanitarian aid.

The Time(lessness) of TB

Chapter 6 focused on the metaphorical representations that both BCH staff and children employed to discuss cumbersome and difficult situations. Children in this chapter were positioned in conversation as: keepers of time, bearers of time, or ‘without time’ if the situation was perceived as particularly dire. Temporal metaphors rendered children and liminality as without time; the biomedical renderings of time no longer provided the structure when social realities came to the fore. In this way time became slippery and unbound by conventional biomedical time-keeping methods, and metaphor acted as a tool to speak to often unthinkable scenarios unfolding in a child’s life. In contrast to Sontag’s criticism of metaphor (1978, 1991), time-related metaphors were vital to comprehend difficult or troubling experiences in what I considered to be a liminal process (Van Gennep 1960).

Thinking about time as a currency – something that can be lost or gained, spent or saved – directly related to how individuals conceived of burden. In contrast to Ndzendze’s (2012) work, time was used as a device with which to understand how burden was verbalised, conceptualised and choreographed through different experiences in Ward 3. All forms of burden were galvanised through temporal experience and the value individuals assigned to time. I built upon Lakoff and Johnson’s seminal work on metaphors (1980) because time as a resource undergirded experiences of burden, and made the distinction between ‘larger’ and ‘smaller’ burdens.

Fundamentally, Ward 3 children were removed from the cadence of their everyday life: familiar rhythms which aided the structure of one's home life and routine fell away when admitted to BCH. One 'falls out of time', or out of synch, when faced with a critical illness. As Stacey and Bryson observe in relation to women's experience of cancer, 'Illness warps time' to a certain extent (2012:5).

Towards a Conclusion: A Million Little Pieces

'The Young Man came to the Old Man seeking counsel.
I broke something, Old Man.
How badly is it broken?
It's in a million little pieces.
I'm afraid I can't help you.
Why?
There's nothing you can do.
Why?
It can't be fixed.
Why?
It's broken beyond repair. It's in a million little pieces.'

- J. Frey (2003:i)

My experiences over my year of research at BCH left me exhausted, depleted and with very little hope for many of the children I worked alongside. Many, like Carlito and Themba, found placement in foster homes, aided by the painstaking work of Victoria and Khaya, Dr. Early and Nurses Lily and Jones and other BCH staff. Others, like Gift, remained at BCH long after my departure, and I do not know where they are now. What is more unsettling is that I do not know how they are coping 'on the outside'. What can one say about an uncertain future when it concerns the smallest of people in the biggest of worlds? How does one approach writing about (often) bleak circumstances and uncertain futures? What does one *do* with a million little pieces and the particularity (and precariousness) of circumstance?

Theresa told me once that:

'...We don't lose children inside Brooklyn. We lose them outside...maybe they come back, maybe they don't. If they're going to die, they die outside after they leave here.'

This, paired with Nurse Jones' parting comments to a discharged patient in December 2012:

'The world outside your mummy's door – they don't care. Listen to your mother. Don't do what others tell you to do. Do what your mummy says, nuh? People is doing nasty things. And it's not your fault and it's not your problem. I've talked too much now, nuh?'

The ‘big world out there’ is replete with challenges – albeit of a different scale – for the children and adults I worked with during 2011-2012. The nurses, teachers and doctors I met during my research continue to try to make a difference in the ways that children experience and are treated for TB at BCH. Many of the children in Ward 3 will continue to take their pills as they have, daily, for the next six to eight to twelve months after this thesis goes to print. Many more – those who left during my time – will continue on in uncertain futures, with very little socio-economic support. They may encounter abuse, they may witness criminal activities in their neighbourhoods, or they may never receive a basic education. The list of potential unknowns they *may* encounter is endless, and I cannot speculate.

As an aspiring medical anthropologist concerned with the often fraught social, economic and political conditions my collaborators face in their lives and especially in South Africa, I realise that I tend to focus on what is ‘broken’, not on what is ‘working’. I want to close with two ethnographic snap shots from the end of my fieldwork.

Nkosi

I drove out to the edges of Khayelitsha, the largest township in Cape Town, to meet Nkosi. It was a month since his discharge from BCH, and I wanted to see how he was adjusting to school and being back at home after his TB treatment. I walked through to the kitchen to unpack groceries I had brought for lunch. As I unpacked biscuits, bread, tea and lunch meat, Vuyi, Nkosi’s older sister, stood at the kitchen table unpacking various pills from their respective plastic bags. Nkosi’s mother explained:

‘She got sick three months after he did...she’s doing ok with the pillis, but she can’t go to school, they won’t let her. This has been a hard year for us. This one (Nkosi) is going to be on treatment for a long time still Kate, yoh. It’s too much...but I thank God he is going to be ok. That place is a home BCH, it’s so much more than a hospital’.

Nkosi explained to me he had a dream. ‘We were all at your house and eating nice things, there was KFC and cool drinks. It was lekker.’

Marissa

January 2013. My cell phone rang and it was Marissa. She had finished her treatment. She called to tell me that she arrived home from Prof. ‘He said I’m right now. No more TB, Kate. My sputums were good and the x-rays are clean.’ Marissa passed the phone to her mother who explained that they were moving away from Blikkie’s Dorp to stay with her in-laws in an area

called Elsie's River. When I asked about Marissa's uncle and whether or not he was taking his TB treatment she said she 'wasn't sure'.

'I don't know Kate...but I'll watch over my girls. We can't expose them to that again mos. We're going to live in a wendy house in the yard. He (Marissa's uncle) has his own wendy house that side, so at least it is separate. It will be ok.'

I asked Marissa if she was excited to move from the blikkie. 'It's not fun there (in Elsie's). I guess it will be ok, but it's not fun. It's boring.'

Despite Marissa's family wanting to maintain independence from the rest of the family in Elsie's River, times were tough, and Marissa's mother needed to consider her daughter's health. Ironically, they moved back into the same house where Marissa was exposed to TB in the first place.

Both vignettes, albeit brief glimpses into uncertain futures, relate the cyclical nature of large macroscopic forces within an intimate scale of microscopic analysis: a kitchen conversation and a telephone call. This is the stuff that is the bedrock of the everyday, the strata, the chinks, the fissures and the unyielding erosive forces. It is difficult (if not painful) to think of life as *not* broken into a million little pieces given these conditions. Although the specific context of South Africa is replete with unique characteristics and precipitating factors, perhaps the only certainty in uncertain times is to say that we are all vulnerable, decidedly so, albeit on different scales. Some futures are more comfortable than others.

This thesis has offered various perspectives on the little pieces of a larger story and epidemic: from paediatric TB patients, their teachers, nurses, physicians, volunteers and in a few instances, their families. Children have been figured in a variety of ways: as patients, as students, as recipients of care, as vulnerable and as those 'with' or 'without' valuable time. It is imperative here to recognise that regardless of the formulation, these categories, objects, or as I have called them here (to borrow the term from Castaneda's (2002) work), these 'figurations' are *anything* but stable. As per Grinker's (2004) suggestions, children often exist in the service of others: the way they interact, are spoken to and definitely the manner in which they are spoken *about*.

Mol (2002) emphasised the multiplicity of the object, and the ways, the practices in which it was *acted upon*. TB and children, in this line of thought, are two entities that are never singular—as evidenced by the various figurations presented throughout in this work, their representations

are always negotiated, told and re-told differently, every time. Livingston argued that cancer in Botswana was something that occurred *between* people; it was always ‘in the making’ as a biomedical, albeit *unstable*, ‘improvised’ object (2012:52, 68). I would like to extend her line of thinking here further. The categories and the ways children and TB are figured into objects of examination or observation are just as unstable, volatile and incredibly unpredictable given the natural ebbs and flows of everyday life, everywhere around the world. As Livingston discriminated between the varied experiences of cancer in the United States and Botswana, so do I discern between the developed ‘first-world’ context and that of South Africa. One simply doesn’t experience childhood (whatever *that* is) or TB in the *same way* in different geographic, social, political, or economic settings. It is a unique experience, contingent upon myriad moving pieces, and they all carry immense weight. As anthropologists, we are tasked to reflect these nuances, and to ensure that there is always space for the acknowledgement, the acceptance, and representation of difference, no matter how many pieces we are trying to reassemble.

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